Program Book

National Center on Birth Defects and Developmental Disabilities

Conference
July 26-28, 2004

Navigating Our Future: Aligning Strategies and Science

Omni Shoreham Hotel
Washington, DC

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The CDC National Center on Birth Defects and Developmental Disabilities wishes to thank the following organizations for their support of its 2004 Conference...

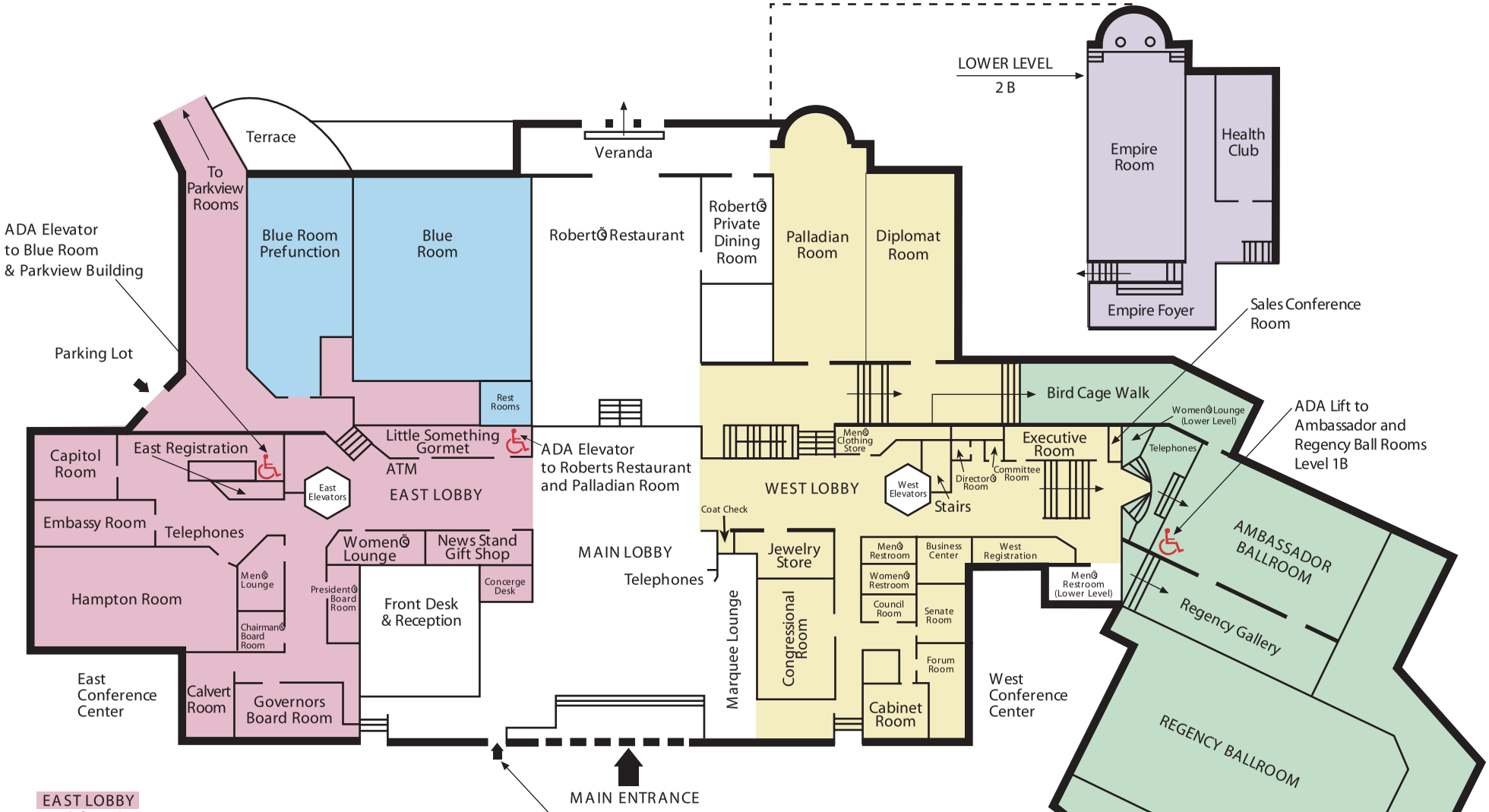
Special Olympics International

The American Association on Health and Disability

The March of Dimes Birth Defects Foundation

The National Association of County and City Health Officials

The Task Force for Child Survival and Development



EAST LOBBY
- Calvert Room
- Capitol Room
- Chairman's Boardroom
- Embassy Room
- Governor's Boardroom
- Hampton Room
- President's Boardroom
- East Registration

WEST LOBBY
- Cabinet Room
- Congressional A&B Room
- Council Room
- Executive Room
- Forum Room
- Sales Conference Room
- Senate Room
- West Registration

BALLROOMS (East Lobby)
- Blue Room
- Blue Pre-Function
- Hampton

BALLROOMS (West Lobby)
- Ambassador Ballroom
- Diplomat Room
- Empire Room
- Palladian Room
- Regency Room

For Access to Diplomat ballrooms
Please use elevators on the West Side and go to level 1B.

For Access to the Empire Ballroom and Health Club/Outdoor Pool
Please use elevators on the West Side of the Hotel and go to level 2B.

OMNI SHOREHAM HOTEL

Conference At-A-Glance

Sunday, July, 25, 2004

8:00 a.m. – 5:00 p.m.	Ancillary Meeting	
	Legacy for Children Annual Meeting	Capitol Room
12:00 p.m. – 8:00 p.m.	Conference Registration	West Registration Desk
3:00 p.m. – 5:00 p.m.	Ancillary Meeting	
	NCBDDD External Partners Group Meeting	Empire Room

Monday, July, 26, 2004

7:00 a.m. – 8:00 a.m.	Continental Breakfast	Regency Ballroom Foyer
8:00 a.m. – 9:30 a.m.	**Opening Session**	Regency Ballroom
	Welcoming Remarks and Distinguished Service Award Presentation	
9:30 a.m. – 10:00 a.m.	Break and Refreshments	Regency Ballroom Foyer
	Exhibits Open	Blue Room
10:00 a.m. – 12:00 p.m.	**Plenary**	Regency Ballroom
	Have We Made Progress in Preventing Fetal Alcohol Syndrome? Insights and Lessons Learned from a 30-Year History	
12:00 p.m. – 1:30 p.m.	**Poster Session with Authors**	Blue Room Pre-Function
	Exhibits	Blue Room
	Lunch On Your Own/Networking (box lunches available for purchase)	
1:30 p.m. – 3:00 p.m.	**Symposia**	
	▪ ***Part One: Newborn Screening: New Challenges and Opportunites; Part Two: Newborn Screening for Intellectual Disability***	Ambassador Ballroom
	▪ ***International Clearinghouse for Birth Defects Monitoring Systems: Past, Present and the Future***	Diplomat Room
	▪ ***Part One: The Power of Parents - Public Health Parenting Interventions to Promote Child Development and Well-Being; Part Two: Transitions and the Medical Home***	Empire Room
	▪ ***Meeting the Challenge: Using Policy to Improve the Public's Health***	Palladian Room
	▪ ***The Prevention of Secondary Conditions in People with Disabilities: What Have We Learned in Ten Years?***	Hampton Room
	▪ ***Information and Resource Centers: A National Approach to Improving the Lives of People with Chronic Conditions and Disabilities***	Congressional Room

Monday, July, 26, 2004, Continued

3:00 p.m. – 3:30 p.m. Break and Refreshments — Foyers to Breakout Rooms

3:30 p.m. – 5:00 p.m. **Contributed Papers Sessions**

- ***Muscular Dystrophy and Other Single Gene Disorders: Focusing Our Public Health Message*** — Ambassador Room
  - Impact of Prenatal and Newborn Screening on Diagnostic Trends in Cystic Fibrosis – United States, 1996-2002
  - Newborn Screening for Duchenne Muscular Dystrophy – Recommendations of an Expert Panel
  - Knowledge and Concern about Respiratory Illness in Males with Duchenne Muscular Dystrophy and Their Parents
  - Mortality in Duchenne Muscular Dystrophy: An Analysis of Multiple Cause Mortality Data, 1983 to 1997
  - The Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet)
- ***Early Hearing Detection and Intervention: Current Status and New Strategies*** — Diplomat Room
  - Efficacy of OAE/ABR Protocol in Identifying Hearing Loss in Newborns
  - Birth Score System and Newborn Hearing Screening in West Virginia
  - Building an Online Bridge to the World of EHDI: An Overview of the CDC-EHDI State Profile
  - Early Hearing Detection and Intervention (EHDI): An Example of Families Partnering with the Public Health Community
  - Audiologists and Early Hearing Detection and Intervention: Surveys from Three States
  - Evaluation of Early Hearing Detection and Intervention-Michigan, 1998-2002
- ***Fetal Alcohol Syndrome: Marketing Prevention, Changing Behaviors, and Assessing Developmental Outcomes*** — Empire Room
  - Developmental/Neurological Profile of Infants in de Aar, Northern Cape, South Africa with Special Emphasis on Those with Fetal Alcohol Syndrome
  - Binge Drinking in the Preconceptional Period and Unintended Pregnancy
  - Competing Discourses of Mothering: Implications for Pregnancy and Alcohol-Related Health Campaigns
  - Effect of a Social Marketing Campaign on African-American Women's Knowledge of Fetal Alcohol Syndrome (FAS)
  - Fetal Alcohol Syndrome: An Innovative Social Action Model
- ***Early Intervention and Child Health*** — Executive Room
  - Understanding Unintended Pregnancy: Improving Infant Health
  - Mediating Effects of Maternal Interaction on Affect Regulation among Infants with Prenatal Alcohol Exposure
  - Association Between Maternity Care Coordination Services and Referral to the Child Service Coordination Program Among Infants with Down Syndrome
  - Framework for Diagnosis and Intervention for Children with Fetal Alcohol Syndrome and Their Families
  - Effectiveness of Early Intervention with Children Prenatally Exposed to Cocaine: Replication with Multiple Cohorts
- ***Impact of the Environment on the Health of People with Disabilities*** — Hampton Room
  - Active Living: How Community Features Can Promote Health for People Who are Blind or Visually Impaired
  - Oases in the Food Desert: Working Toward Access to Healthy Food for People with Disabilities
  - Disability and Public Health Project: Creating a Curriculum
  - Understanding the Contextual Factors that Influence the Presence of Secondary Conditions for People Who Experience Spinal Cord Injuries
  - Development of Accessibility Instruments Measuring Fitness and Recreation Environments (AIMFREE) for People with Disabilities
- ***Evaluating Risk Factors for Birth Defects*** — Congressional Room
  - The National Smallpox Vaccine in Pregnancy Registry: Update on Women Inadvertently Exposed to Smallpox Vaccine and Their Early Pregnancy Outcomes
  - Placental Glutathione-S-Transferase PI Activity and Genotype in a Population of Hispanic Women
  - New Estimates of the Effect of Prenatal Smoking on the Risk of Heart Defects
  - Gastroschisis in Utah: A Population-Based Study of BMI and Seasonality
  - Periconceptional Dietary Intake of Choline and Betaine and Neural Tube Defects in Offspring

5:00 p.m. – 7:00 p.m. Ancillary Meeting
National Information and Resource Center Directors Meeting — Committee Room

7:00 p.m. – 9:00 p.m. **Reception** — Palladian Room

Tuesday, July, 27, 2004

6:30 a.m. – 8:00 a.m. Networking Breakfast — Ambassador Ballroom

8:00 a.m. – 9:30 a.m. **Plenary** — Regency Ballroom

Implications for Advances in Genomics to Public Health Research and Prevention

9:30 a.m. – 10:00 a.m. Break and Refreshments — Regency Ballroom Foyer

Exhibits Open — Blue Room

10:00 a.m. – 11:30 a.m. **Symposia**

- ***Integrating Child Health Information Systems*** — Ambassador Ballroom
- ***New Concepts in Infectious Causes of Birth Defects and Developmental Disabilities*** — Diplomat Room
- ***Creating Effective Communication Campaigns: Lessons from the Field*** — Empire Room
- ***The Health of People with Intellectual Disabilities: A Multidimensional Approach to Understanding and Addressing the Problem*** — Palladian Room
- ***Caregiving in America as an Emerging Public Health Issue: Surveillance and Response by the Nation's Public Health System*** — Hampton Room
- ***Advancing Public Health Priorities Through Advocacy*** — Congressional Room

11:30 a.m. – 1:30 p.m. **Awards Program and Luncheon** — Regency Ballroom

2:00 p.m. – 3:30 p.m. **Contributed Papers Sessions**

- ***New Horizons for Prenatal and Neonatal Screening*** — Ambassador Ballroom
  - Expanded Newborn Screening: The Mississippi Experience
  - Neonatal Screening Program by Tandem Mass Spectrometry in a Mexican Population
  - First PAGE: A Strategy for Screening for Birth Defects and Genetic Disorders in a Primary Prenatal Care Setting
  - Attitudes Toward Prenatal Testing Among Texas Women
  - Prevalence of 2-Methylbutyrl-COA Dehydrogenase Deficiency (MBADD) Identified by Newborn Screening in the Hmong-American Population of Wisconsin
- ***Risk Factors for Autism Spectrum Disorders*** — Diplomat Room
  - Investigating Linkage of Autism Spectrum Disorder Surveillance Data to Hazardous Air Pollutant Data
  - Using Geographic Information Systems to Link Data from the South Carolina Autism and Developmental Disabilities Monitoring Network with Available Environmental Data
  - MTHFR Polymorphism, Epigenetics, and Risk for Autism
  - Maternal Autoimmune and Allergic Diseases and Childhood Autism
- ***Folic Acid Promotion: Modifying Behaviors in Special Populations and Assessing the Effectiveness of Interventions*** — Empire Room
  - Health Care Professionals Awareness and Practics Regarding Folic Acid
  - Spanish-Language Folic Acid Media Campaign–Increasing Knowledge and Changing Behavior Among Hispanic Women of Childbearing Age
  - Evidence on Effectiveness of Folic Acid Fortification: Results from a Systematic Review for the Guide to Community Preventive Services
  - Improving Preconceptional Folic Acid Intake Among College-Aged Women of Childbearing Age
  - Prevalence of Multivitamin Use–New Data from the Pregnancy Risk Assessment Monitoring System (PRAMS), 2000

Tuesday, July, 27, 2004, Continued

2:00 p.m. – 3:30 p.m. **Contributed Papers Sessions, Continued**

- ***Health Promotion and Access to Care for People with Disabilities*** Palladian Room
  - Missed Appointment Parameters Among Children and Adults with Disabilities
  - Improving Access to Breast Cancer Screening for Women with Physical Disabilities
  - Designing Community-Based Strategies to Improve Primary Prevention for People with Physical Disabilities in Virginia: Focus Group Findings
  - Finding the Needle in the Haystack: Using a Touch Screen Computer System to Collect Low Base Rate Healthcare Utilization Information
- ***Health Status and Quality of Life Among Persons with Disabilities*** Hampton Room
  - Adverse Health Behaviors and Chronic Conditions in Adults with Disabilities
  - Smoking Status and Quality of Life: A Longitudinal Study Among Adults with Disabilities
  - Increased Injury Risk Among People With Disabilities
  - Obesity, Quality of Life and Disability Among Youth: A Report from the Washington State Healthy Youth Survey 2002
  - Preference Ratings for Health and Disability States are Different for People with Disabilities Compared to the General Population
- ***Birth Defects Surveillance: Improving Methods and Use of Data*** Congressional Room
  - Development of Indiana Birth Defects Surveillance System Educational Program for Hospital Staff at Birthing Hospitals in Indiana
  - Results of Neural Tube Defects Case Ascertainment Process Combining Vital Records Datasets and Birth Defects Surveillance Data, for Years 1996 through 2001, in Puerto Rico
  - Multi-Center Study for Birth Defects Monitoring Systems in Korea
  - Congenital Heart Defects in Utah: Type of Pregnancy Outcome and Timing of Diagnosis Impact Completeness and Reporting
  - Omphalocele and Gastroschisis: Black-White Disparity in Infant Survival

3:30 p.m. – 4:00 p.m. Break and Refreshments Foyers to Breakout Rooms

4:00 p.m. – 5:30 p.m. **Symposia**

- ***Improving the Identification of Children with Developmental Disabilities (Including Autism Spectrum Disorders): Models for Early Screening*** Ambassador Ballroom
- ***Challenges and Opportunities in Developing an Integrated State MCH Surveillance System: The Role of Birth Defects Surveillance*** Diplomat Room
- ***Over-the-Counter Medication Use in Pregnancy*** Empire Room
- ***Reducing Secondary Conditions Among People with Spina Bifida*** Palladian Room
- ***A Model for Regional Systems of Care to Promote Health and Well-Being for Persons with Rare Genetic Disorders*** Hampton Room
- ***From Grassroots to the Steps of the Supreme Court: Developing and Implementing Disability Policy at the Community, State and National Level*** Congressional Room

7:30 p.m. – 9:30 p.m. **NCBDDD Strategic Planning Partners Forum** Empire Room

Wednesday, July, 28, 2004

7:30 a.m. – 8:30 a.m. Continental Breakfast — Regency Ballroom Foyer

8:30 a.m. – 10:00 a.m. **Symposia**

- ***Missed Opportunities to Improve Pregnancy Outcomes: Recommended Pre-Conception Care*** — Empire Room
- ***Living Well with a Disability: Development, Implementation and Evaluation of a Nationally Recognized Health Promotion Intervention for Adults with Disabilities*** — Ambassador Ballroom

8:30 a.m. – 10:00 a.m. **Contributed Papers Sessions**

- ***Autism Surveillance: Improving Methodology and Use of Data*** — Diplomat Room
  - Methodology for Multiple Source, Population-Based Surveillance of the Autism Spectrum Disorders (ASDs) in the United States ADDM CADDRE Network
  - Modeling Clinical Outcome of Autistic Spectrum Disorders
  - Differentiating Between Autism Spectrum Disorders and Other Developmental Disabillities Using the Modified Checklist for Autism in Toddlers (M-CHAT)
  - Investigating Developmental Delays Study: Comparison of SCQ and PDDST
  - PDQ-1 and ABC as Autism Screeners
- ***Children with Disabilities*** — Palladian Room
  - Physical and Psychosocial Health for Children with Spina Bifida
  - Adolescent Knowledge and Health Practices I the US Hemophilia Population: National Hemophilia Foundation Baseline Study and Adolescent Health Campaign
  - The Acquisition of Adult Social Roles among Young Adults with Developmental Disabilities
  - FAMILY MATTERS:Using Bright Futures to Promote Health and Wellness for Children with Disabilities
  - Medical Home Implementation through Community-Based, Primary Care Practices: Moving to the Next Level
- ***Evaluating Risk Factors for Birth Defects: Medication and Supplement Use*** — Congressional Room
  - Periconceptional Exposure to Oral Contraceptives and the Risk of Neural Tube Defects
  - Hypospadias and Maternal Intake of Progestins and Oral Contraceptives
  - Loratadine (Claritin®) and Hypospadias, Data from the National Birth Defects Prevention Study, U.S.A. 1997-2000
  - Medication Use in Pregnancy: 1976-2000
  - Herbal Use in Pregnancy: Results from Two Studies
- ***Health Communications: Improving Identification and Care through Education and Training*** — Hampton Room
  - Do Pediatric Residents Know the Five Areas of Development?
  - Pediatricians' Knowledge and Practice Behavior Regarding Fetal Alcohol Syndrome and Other Prenatal Exposure Disorders
  - A National Project to Educate Primary Care Providers About Down Syndrome: Defining Training/Information Needs, Preliminary Results
  - Transcultural Training for Community-Based Perinatal Health Care Providers

10:00 a.m. – 10:30 a.m. Break and Refreshments — Regency Ballroom Foyer

10:30 a.m. – 12:00 p.m. **Closing Session** — Regency Ballroom

Personal Perspectives on Disability: Experiences Across the Lifespan

Wednesday, July, 28, 2004, Continued

8:00 p.m. – 4:00 p.m.	Ancillary Meeting **Early Hearing Detection and Intervention (EHDI) Federal Interagency Advisory Committee Meeting**	Embassy Room
1:00 p.m. – 4:00 p.m.	Ancillary Meeting **Center for the Evaluation of Risk to Human Reproduction (CERHR) Committee Meeting**	Committee Room
1:00 p.m. – 5:00 p.m.	Ancillary Meeting **Disability and Health State Grantees Meeting**	Empire Room
1:00 p.m. – 6:00 p.m.	Ancillary Meeting **NBDPN Executive Committee**	Ambassador Room
1:00 p.m. – 8:00 p.m.	Ancillary Meeting **National Council on Folic Acid Meeting**	Diplomat Room
1:00 p.m. – 9:30 p.m.	Ancillary Meeting **Autism and Developmental Disabilities Monitoring (ADDM) Network and Centers for Autism and Developmental Disabilities Research Epidemiology (CADDRE) Surveillance Meeting**	Executive Room

Thursday, July, 29, 2004

8:00 a.m. – 4:00 p.m.	Ancillary Meeting **Disabilities and Health State Grantees Meeting**	Empire Room
8:00 a.m. – 5:00 p.m.	Ancillary Meeting **Autism and Developmental Disabilities Monitoring (ADDM) Network and Centers for Autism and Developmental Disabilities Research Epidemiology (CADDRE) Surveillance Meeting**	Executive Room

* Ancillary Meetings are generally by invitation only and are arranged by various individuals, groups, funded partners, or constituents.

Internal Scientific Planning (ISP) Committee

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Juliana Cyril, MPH, PhD
Nicole Dowling, PhD
Kate Galatas, MPH
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General Information

Conference Highlights

The following subthemes served as a framework for conference planning and are touchstones for effective public health action:

- Keynote addresses by national leaders, dignitaries, and others.
- Plenary sessions on major birth defects, developmental disabilities, bleeding disorders, and disability and health issues.
- Concurrent sessions on specific, high-priority topics.
- Creative partnering.
- Communicating with policy makers and creating policy change.
- Emerging issues.
- Translating research to practice.
- Research and evaluation methods for new initiatives.

Plenary Highlights

Day 1

Opening Plenary

The opening session includes introductory remarks by Jennifer House, PhD, President of March of Dimes, Donna F. Stroup, PhD, Director of the new Coordinating Center for Health Promotion of CDC, and José F. Cordero, MD, MPH, Director of the CDC's National Center on Birth Defects and Developmental Disabilities.

Morning Plenary

The morning begins with an exciting plenary discussion entitled *Have We Made Progress in Preventing Fetal Alcohol Syndrome? Insights and Lessons Learned from a 30-year History*. Moderated by Kenneth Warren, PhD, National Institute on Alcohol, Abuse, and Alcoholism, National Institutes of Health. Presenters include Kenneth Lyons Jones, MD, University of California, San Diego School of Medicine; Raul Caetano, MD, MPH, PhD, University of Texas School of Public Health; and Kathleen T. Mitchell, MHS, CCDC, National Organization on Fetal Alcohol Syndrome.

Day 2

Morning Plenary

Presenters include Alan Guttmacher, MD, National Human Genome Research Institute, National Institutes of Health; and Bartha Knoppers, MA, LLB, BCL, DLS, PhD, Université de Montréal.

Day 3

Closing Plenary

Presenters include Lex Frieden, MA, The Institute for Rehabilitation and Research and Rick Rollens, M.I.N.D. Institute.

Conference Goals

- Provide a forum for input into the NCBDDD strategic plan and research agenda.
- Identify and share cutting edge science in NCBDDD disease prevention activities.
- Facilitate collaboration among NCBDDD's various partners in achieving its strategic agenda.

Conference Themes

- Promoting early identification of genetic and developmental conditions.
- Understanding the causes, occurence, and consequences of birth defects, developmental disabilities and heritable blood disorders.
- Preventing birth defects and developmental disabilities.
- Reducing secondary conditions among people with disabilities and heritable blood disorders.
- Promoting health and well-being among persons with disabilities.
- Translating knowledge about prevention to public health policy and programs.
- Promoting cutting-edge science, particulary, in defining biomarkers of exposure or disease and examining environmental and genetic interactions.

Conference Cost

Early Registration (including payment and form by **July 21, 2004**)	$195
On-Site Registration	$225
Student Registration	$ 95
Continuing Education Credits	$ 50

Please wear your name badge at all times.

Payment Method

VISA, American Express, and MasterCard are accepted, as are purchase orders or checks. Payment must be included with your registration. Registration includes all materials, access to sessions and exhibits, continental and networking breakfasts and breaks each day, the Monday evening reception, and the Awards Program and Luncheon on Tuesday.

Participant Substitutions

If you are unable to attend the conference, you may send a substitute. Substitutions can be made at any time, including on-site at the conference for no additional fee.

Cancellations

Cancellations made in writing on or before **June 30, 2004,** will be refunded minus a $75 administrative fee. No refund will be provided after the deadline.

Continuing Education Credits

Continuing Education Units (CEU's) will be offered for various professions based on an estimated 14 hours of instruction. Units will be given only to those persons who attend sessions and complete the required documentation. Participants can register for CEU's on-site. A fee of $50 will be charged for those persons wishing to receive CEU's.

Hotel Reservation Information

The conference hotel is the Omni Shoreham Hotel, 2500 Calvert Street, NW, Washington, D.C. 20008, Telephone: (202) 234-0700 or for direct reservations: (202) 756-5125, fax (202) 756-5120. Guest fax (for faxes to participants): (202) 234-0015. Check-in is 3:00 pm/Check-out is 12:00 Noon.

We have blocked rooms for this meeting at the following rates:

- Single Occupancy: (exclusive of taxes) is at the prevailing federal government per diem (subject to change), currently $150.00.
- Double Occupancy: (exclusive of taxes) is based upon the prevailing federal government per diem (subject to change) of $150.00 plus a $20.00 extra person surcharge, currently $170.00.

Reservations must be made directly with the hotel no later than Saturday, July 3, 2004, to ensure room availability and to receive the conference room rate. To receive the conference room rate, you must inform the hotel reservation staff that you are calling for the group rate for the ***NCBDDD Conference***.

Travel Arrangements

Diplomat Travel is the official travel agency for the National Center on Birth Defects and Developmental Disabilities 2nd Conference. To reserve your flight, you can reach Valerie Duston at Diplomat Travel by e-mail at valeried@diplomattravel.com or on their toll-free number at (800) 476-2333 between the hours of 9:00 a.m. and 4:30 p.m. (EST).

Ground Transportation

The hotel is located about 20 minutes from Reagan National Airport (and just 1/2 a block from the Metro stop). You have several transportation options from Reagan National Airport. Take the Metro (yellow line in the direction of Mount Vernon Square) to Gallery Place/Chinatown. Change to the red line in the direction of Shady Grove. Take red line to Woodley Park/Zoo/Adams Morgan stop. Hotel is located half a block from the metro (fare is $3). Or, take a taxi (about $20) or the SuperShuttle from the Ground Transportation Level. Round trip shuttle service on the Super Shuttle is $20 from Reagan National Airport.

From Dulles or Baltimore/Washington airports take the SuperShuttle located on the Ground Transportation Level directly to the hotel. Taxis are also available at about $60-80 one-way.

SuperShuttle fares one-way fares are below:

To/From Reagan National	$9
To/From Dulles	$25
To/From Baltimore/Washington	$35

Conference Check-In

The conference registration and information desk, located on the hotel's West Lobby, will be open the following hours during the week of the conference:

- Sunday, July 25, 2004
  12:00 Noon to 8:00 p.m.
- Monday, July, 26, 2004
  7:00 a.m. to 6:00 p.m.
- Tuesday, July, 27, 2004
  7:00 a.m. to 6:00 p.m.
- Wednesday, July, 28, 2004
  8:00 a.m. to 4:00 p.m. (ancillary meeting registration begins at 1:30 p.m.)
- Thursday, July, 29, 2004
  8:00 a.m. to 12:00 noon (ancillary meeting registration)

Exhibits

Please plan to tour the exhibits in the Blue Room located in the hotel's East Wing. If your organization would like to exhibit at the conference, contact Angeline Lewis by phone at (404) 633-6869 or by e-mail at a_lewis@psava.com.

Other Activities

Many exciting, entertaining, and healthy activities are planned for the conference in Washington, D.C. A full-service spa and fitness center is available within the Omni Shoreham Hotel. Walking and jogging opportunities will be available on the Rock Creek Park jogging paths adjacent to the conference hotel.

Special Activities

Continental and Networking Breakfasts and Breaks
Opportunities exist to network during the breakfasts and breaks planned each day.

Welcome Reception
A reception to welcome all conference participants will be held Monday, July 26, 2004, from 7:00 p.m. to 9:00 p.m. at the hotel. Don't miss this opportunity to network with colleagues.

Awards Luncheon
An awards program and luncheon is planned for all conference participants on Tuesday, July 27, 2004. This is an opportunity for CDC to acknowledge the outstanding contributions of its colleagues, partners, and others in promoting the health of babies, children, and adults, and enhancing their full potential for full, productive living.

Other Places of Interest

Adams Morgan Neighborhood:
Centered on 18th Street and Columbia Rd, NW, Adams Morgan is synonymous with entertainment and diverse dining. Ethnic restaurants, nightclubs, and bars line the two streets filled with vibrant Latino and African communities that lend an international flavor to this electric neighborhood.

Dupont Circle Neighborhood:
The hub of cosmopolitan Washington. Victorian row houses and Beaux-Arts mansions have been restored to house embassies, international restaurants, art galleries, and museums. Some museums include The Phillips Collection, the Woodrow Wilson House, the Textile Museum and the National Geographic Society's Explorers Hall. Just a quick walk down Connecticut Avenue, culture and entertainment collide on the circle at the many cafes and shops.

Georgetown:
Once a thriving colonial port, Georgetown is now a prime example of an intact historical community. Centered on Wisconsin and M Streets, NW, the community is most renowned for shopping, dining, and nightlife as well as the university that shares its name. Dumbarton House, Tudor Place Historic House and Garden, the C&O Canal, Old Stone House, and Dumbarton Oaks represent the area's history beyond the boutiques and antique shops.

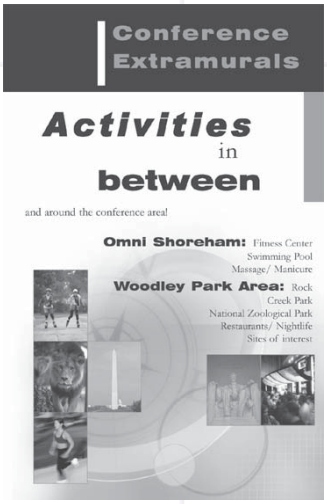
Capitol Hill:
Bustling with fabulous restaurants and cafes, shops, and galleries, Capitol Hill is the place to dine, shop, and even celebrity-spot. Hill attractions include the Botanic Gardens, the Capitol Building, the House of Representatives, the Supreme Court, the Library of Congress, and the Smithsonian Museums.

Old Town Alexandria:
Once a principal colonial trading center and port, Alexandria's "Old Town," which is almost 50 years older than the city of D.C., is one of America's most historic communities. With over 200 restaurants and pubs in a 15-block radius, there's something for everyone.

Arlington National Cemetery:
America's largest national burial ground, with more than 600 acres of landscaped hills. Among the thousands of white headstones are the graves of President John F. Kennedy and the Tomb of the Unknowns. Open daily 8 a.m. - 5 p.m. Free admission. Metro Arlington Cemetery. http://www.arlingtoncemetery.net.

Metrorail is the safest, cleanest, and most efficient way to get around D.C. Train lines are named for colors: red, yellow, blue, green, and orange. Metro opens at 5:30 a.m. Mon–Fri and 8:00 a.m. on Saturday and Sunday. Metro closes at midnight Sunday through Thursday and 2:00 a.m. Friday and Saturday.
http://www.wmata.com.

For more information about Washington, D.C., visit http://www.washington.org or look for the flyer (below) in your conference bag.



Program Events
Monday, July 26, 2004

7:00 a.m. – 8:00 a.m.	Continental Breakfast	Regency Ballroom Foyer
8:00 a.m. – 9:30 a.m.	Opening Session	Regency Ballroom
9:30 a.m. – 10:00 a.m.	Breaks and Refreshments Exhibits	Regency Ballroom Foyer Blue Room
10:00 a.m. – 12:00 p.m.	Plenary	Regency Ballroom
12:00 p.m. – 1:30 p.m.	Poster Sessions with Authors Exhibits **Lunch On Your Own** **(box lunches available for purchase)**	Blue Room Pre-Function Blue Room
1:30 p.m. – 3:00 p.m.	Symposia	See Pages 19-24
3:00 p.m. – 3:30 p.m.	Breaks and Refreshments Exhibits	Foyers to Breakout Rooms Blue Room
3:30 p.m. – 5:00 p.m.	Contributed Papers Sessions	See Pages 25-30
5:00 p.m. – 7:00 p.m.	Ancillary Meeting **National Information and Resource Center Directors Meeting**	Committee Room
7:00 p.m. – 9:00 p.m.	**Reception**	Palladian Room

Opening Plenary

8:00 a.m. – 9:30 a.m. ***Welcoming Remarks*** Regency Ballroom

Moderator
Barbara R. Holloway, MPH
Deputy Director, National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

Presenters
Jennifer L. Howse, PhD
President
March of Dimes

Donna F. Stroup, PhD
Acting Director, Coordinating Center for Health Promotion
Centers for Disease Control and Prevention

José F. Cordero, MD, MPH
Director, National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

CDC Distinguished Service Award Presentation

Presenter
Barbara Alving, MD
Acting Director, National Heart, Lung, Blood Institute
National Institutes for Health

Awardee
Bruce Evatt, MD
Former Director, Division of Hereditary Blood Disorders, National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

Comments on Scientific Proceedings
Mary E. Northridge, PhD, MPH
Editor-in-Chief
American Journal of Public Health

9:30 a.m. – 10:00 a.m. Break and Refreshments Regency Ballroom Foyer

10:00 a.m. – 12:00 p.m. **Plenary** Regency Ballroom

Have We Made Progress in Preventing Fetal Alcohol Syndrome? Insights and Lessons Learned from a 30-Year History

Moderator
Kenneth Warren, PhD
Director, Office of Scientific Affairs
National Institute on Alcohol, Abuse, and Alcoholism

Presenters
Kenneth Lyons Jones, MD
Professor, Pediatrics
University of California, San Diego School of Medicine

Raul Caetano, MD, MPH, PhD
Assistant Dean and Professor
University of Texas School of Public Health

Kathleen T. Mitchell, MHS, CCDC
Program Director and National Spokesperson
National Organization on Fetal Alcohol Syndrome

The prevention of fetal alcohol syndrome (FAS) continues to pose a challenging problem for public health after three decades of effort. The challenges include barriers to detection of FAS and other fetal alcohol spectrum disorders (FASD) at the community level; continuing trends in hazardous alcohol use by childbearing-aged women and high relapse rates among heavy users; and the difficulties involved in moving evidence-based knowledge to practice. This plenary session will delve more deeply into the barriers to be overcome as well as strategies and programs that can potentially impact the number of children born with birth defects and developmental disabilities caused by prenatal alcohol exposure.

12:00 p.m. – 1:30 p.m. Lunch on Your Own (box lunches available for purchase)
Poster Presentations Blue Room Pre-Function
(see pages 13 - 18)

Poster Presentations

12:00 p.m. – 1:30 p.m. **Poster Presentations** Blue Room Pre-Function

AUTISM: RESEARCH, SURVEILLANCE

[P-01] **Approaches for Evaluation of Multiple Source, Population-Based Surveillance of the Autism Spectrum Disorders (ASD's) in the United States**
***Jon Baio and Kim van Naarden Braun**, Centers for Disease Control and Prevention*

[P-02] **Epidemiology of Autism Among California-Born Twins**
***Judith Grether**, California Department of Health Services*

[P-03] **Overview of the Modified Checklist for Autism in Toddlers (M-CHAT)**
***Thyde Dumont-Mathieu**, University of Connecticut, Department of Psychology*

[P-04] **Predictors of Early Diagnosis in Autism Spectrum Disorders**
***Laura Arnstein**, Medical University of South Carolina*

[P-05] **Satisfaction with Service Use by Families with a Child with Autism**
***Kathleen Thomas**, University of North Carolina at Chapel Hill*

[P-06] **The Co-Occurrence of Autism and Birth Defects**
***Diana Schendel**, Centers for Disease Control and Prevention*

[P-07] **The Prevalence of Autism in Special Education**
***Paul Shattuck**, Waisman Center, University of Wisconsin*

[P-08] **Using Geographic Information Systems to Link Data from the South Carolina Autism and Developmental Disabilities Monitoring Network with Available Environmental Data**
***Lydia Buxbaum King**, Medical University of South Carolina*

[P-09] **New Jersey Answers for Autism Survey: Initial Findings From An ASD Database**
***Walter Zahorodny**, New Jersey Medical School*

BEHAVIORAL SCIENCE AND HEALTH COMMUNICATION RESEARCH AND APPLICATION

[P-10] **"In Their Own Words:" The Uses of Personal Stories to Assess Program Impact**
***Kate Wilson**, Centers for Disease Control and Prevention*

[P-11] **A Retrospective Process Evaluation of a Spanish-Language Folic Acid Media Campaign: Tracking Trials and Tribulations**
***Elizabeth Fassett**, Centers for Disease Control and Prevention*

[P-12] **Developing Health Education Materials for Populations with Low Literacy Skills: Lessons Learned from "Emma's Story", An Easy to Read Story About Folic Acid and Preventing Birth Defects**
***Katie Kilker**, Battelle Contractor, Centers for Disease Control and Prevention*

[P-13] **Development of the Tennessee Genetics and Newborn Screening Website**
***David Hollar**, University of Tennessee, Developmental and Genetic Center*

BEHAVIORAL SCIENCE AND HEALTH COMMUNICATION RESEARCH AND APPLICATION, cont'd

[P-14] **Science Ambassador Program**
***Heather K. Carter and Alison B. Nair**, Centers for Disease Control and Prevention*

[P-15] **What is the Public Asking About Early Hearing Detection and Intervention?**
***Marcia Victor**, Centers for Disease Control and Prevention*

[P-16] **Recurrence Prevention Campaign: Social Marketing Efforts and Progress**
***Adriane Griffen**, Spina Bifida Association of America*

BIRTH DEFECTS: RESEARCH, SURVEILLANCE, AND PREVENTION

[P-17] **A Different View of Birth Defects as a Cause of Mortality: Using Birth Defects Registry Data to Evaluate the Full Effect of Birth Defects on Infant and Childhood Mortality and Determine the Cause of Death Distribution among Children with Birth Defects**
***Glen Copeland**, State of Michigan, Vital Records and Health Data*

[P-18] **Asthma, Asthma Medication Use and Risk of Cardiovascular Malformations in the National Birth Defects Prevention Study**
***Erin Bell**, University of Albany, School of Public Health*

[P-19] **Burden of Congenital Rubella Syndrome Following A Community Outbreak of Rubella Among School-Age Children, Recife, Pernambuco, Brazil, 1999-2000**
***Tatiana Lanzieri**, Secretary of Health Surveillance (SVS), Ministry of Health*

[P-20] **Connecting Birth Defect Surveillance with Available Services in Minnesota**
Barbara Frohnert and ***Daniel Symonik**, Minnesota Department of Health*

[P-21] **Development of Assay for Adult and Adolescent Biomarkers of CRS**
***Kahn Rhrissorrakrai**, Centers for Disease Control and Prevention*

[P-22] **Down Syndrome Prevalence in Hungary After Chernobyl's Nuclear Power Plant Accident**
***Janos Sandor**, University of Pecs*

[P-23] **Evaluation of the Metropolitan Atlanta Congenital Defects Program (MACDP)**
***Laura Williams,** Centers for Disease Control and Prevention*

[P-24] **Seasonality and Excess Incidence in MACDP**
***Clinton Alverson**, NCBDDD, Centers for Disease Control and Prevention*

[P-25] **Spatial Analysis of Birth Defects in Atlanta**
***Csaba Siffel**, Centers for Disease Control and Prevention*

[P-26] **Surveillance of Orofacial Clefts in Victoria, Australia from 1983 through 2000: A Report Using the Victorian Birth Defects Register**
***Linda Vallino-Napoli**, Alfred I. DuPont Hospital for Children*

[P-27] **Texas Survey and Biologics Participation Rates in the NBDPS**
***Michael Voloudakis**, Public Policy Research Institute, Texas A&M University*

[P-28] **Utilization of Birth Defects Data through Collaborative Research Projects**
***Samara Viner-Brown,** Rhode Island Department of Health*

BIRTH DEFECTS: RESEARCH, SURVEILLANCE, AND PREVENTION, cont'd

[P-29] **Validation of Information on Birth Defects Registry with Vital Records**
***Chunfu Liu**, Connecticut Department of Health*

CHILD DEVELOPMENT AND DEVELOPMENTAL SCREENING

[P-30] **Assessing the Predictive Validity of a Kindergarten Screening Battery**
***Marcia Scott**, University of Miami*

[P-31] **Effectiveness of Preschool Screening at Identifying Children with Disabilities**
***Christine Delgado**, University of Miami*

[P-32] **How Many Children with Delays in Development Do Doctors Find?**
***Mary Pavan**, University of South Florida, College of Medicine*

[P-33] **Improving Child Find: Process and Products from Five States**
***Beppie Shapiro,** University of Hawaii*

[P-34] **Medical and Developmental Factors Associated with OCD Classes**
***Marco Grados**, Johns Hopkins School of Medicine*

DEVELOPMENTAL DISABILITIES: RESEARCH, SURVEILLANCE, AND PREVENTION

[P-35] **Effectiveness of Several Interventions and Reinforcement on Oral Health Persons with Intellectual and/or Developmental Disabilities**
***Donna Bainbridge**, The University of Montana Rural Institute*

[P-36] **Examining Variability in the Consumption of Medications Commonly Used to Treat Attention-Deficit/Hyperactivity Disorder (ADHD): Regional Consumption of Amphetamine-Based Medications, 1997 to 2001.**
***Christine Kennedy**, **Catherine A. Lesesne**,* and ***Susanna Visser**, Centers forDisease Control and Prevention* and ***Ann Abramowitz**, Emory University*

[P-37] **Long Term Effects of Early Intervention with Children Prenatally Exposed to Cocaine**
***Angelika Claussen**, Centers for Disease Control and Prevention* and ***Katherine Bono**, Linda Ray Intervention Center, University of Miami*

DISABILITY AND HEALTH

[P-38] **A Preliminary Study of DXA Positioning Protocols for Women and Girls with Mobility Disabilities**
***Margaret Turk**, State University of New York Upstate Medical University*

[P-39] **Assistive Technology and Adolescents with Spina Bifida**
***Brian Dudgeon**, University of Washington*

[P-40] **Health Inequalities in New Mexico: Policy Implications for Disability and Health Policy in Rural States**
***Anthony Cahill**, University of New Mexico School of Medicine* and **Judith Liddell**,*Center for Development and Disability*

[P-41] **Living with Multiple Sclerosis in the United States and Germany: Consumers' Experiences with Health Care Services**
***Thilo Kroll**, NRH Center for Health and Disability Research*

[P-42] **Parental Reports of Child Disability: Data From the 2001-02 National Health Interview Surveys**
***Patricia Pastor**, Centers for Disease Control and Prevention*

DISABILITY AND HEALTH, cont'd

[P-43] **Promoting Health and Wellness for Persons with Disabilities in 16 States**
***Roberta Carlin**, American Association on Health and Disability*

[P-44] **The Health and Secondary Conditions Surveillance Instrument for Adults with Developmental Disabilities (HSCIADD) and Consumer Involvement in the Completion Process**
***Meg Traci**, The University of Montana Rural Institute*

[P-45] **Using Community-Based Participatory Action Research (PAR) in Disability Health Promotion**
***Melinda Neri,** NRH Center for Health and Disability Research*

[P-46] **Direct Service Staff Turnover in Private Sector Corporations Serving Persons with Developmental Disabilities**
***Donna Bainbridge**, The University of Montana Rural Institute*

[P-47] **The Effects of Parenting Practices, Maternal Depression and Other Sociodemographic Variables on Behavioral Health in White, African American and Latino Children**
***Lee Pachter**, University of Connecticut School of Medicine*

[P-48] **Development of Accessibility Instruments Measuring Fitness and Recreation Environments (AIMFREE) for People with Disabilities**
***Edward Wang**, **Amy Rauworth** and **Barth Riely**, University of Illinois at Chicago*

[P-49] **Increasing Access to Preventive Services for Women with Disabilities: The Accessible Tables Project**
***Larry Steele**, New York State Department of Health*

FETAL ALCOHOL SYNDROME: DIAGNOSIS, SURVEILLANCE, PREVENTION, MANAGEMENT

[P-50] **Biomarkers of Alcohol Abuse in Pregnant Women as Risk Indicators for the Development of FAS and FASD**
***Kathleen Strauss**, University of Maryland*

[P-51] **Change in Alcohol Consumption Among Latinas of Reproductive Age**
***Christina Chambers**, University of California, San Diego*

[P-52] **Evaluation of Ascertainment Sources for Fetal Alcohol Syndrome (FAS): What Combination Results in the Greatest Yield?**
***Deborah Fox**, New York Department of Health*

[P-53] **Mother/Infant Genetic Profiles for ADH2 as Risk Indicators for the Development of FAS and FASD**
***Jan Powell**, University of Maryland*

[P-54] **N2-Ethylguanine DNA Adduct as a Risk Indicator for FAS and FASD: A Case Study**
***Stacy Gelhaus**, University of Maryland*

[P-55] **Prevention/Intervention Programs for Fetal Alcohol Syndrome (FAS) in South Africa: What Have We Learnt So Far?**
***Stephanie Schon**, University of Witwatersrand*

FOLIC ACID

[P-56] **Effect of Brief Physician Counseling on Women's Use of Folic Acid Supplements**
***Bridget S. Mosley**, University of Arkansas for Medical Sciences*

[P-57] **Epidemiology of NTD Cases Four Years After a Folic Acid Campaign in Nuevo Leon Mexico**
***Laura Martinez**, Medical School University of Nuevo Leon*

[P-58] **Folic Acid Awareness, Knowledge and Use by Women of Childbearing Age in the United States, 1995 - 2003**
***Kathleen Raleigh** Centers for Disease Control and Prevention*

[P-59] **Hospitalizations of Infants with Birth Defects in the United States Before and After Fortification of Grains with Folic Acid**
***James Robbins**, Arkansas Center for Birth Defects Research and Prevention*

[P-60] **Livebirths with Neural Tube Defects: Combined Impact of Prenatal Diagnosis and Folic Acid Utilization**
***Laurie Seaver**, Greenwood Genetic Center*

[P-61] **Folic Acid Use During Pregnancy and Child Behavior-Sino-U.S. NTD Prevention Project**
***Jacqueline Gindler**, NCBDDD, Centers for Disease Control and Prevention*

[P-62] **Misclassification of Strong Conounders: Art, Folic Acid and the Occurence of Twin Births**
***Owen Devine**, Centers for Disease Control and Prevention*

[P-63] **Folic Acid Use and Knowledge Among Women of Childbearing Age in Florida**
***Kathleen McDuffie**, Centers for Disease Control and Prevention*

NEWBORN SCREENING AND FOLLOW-UP: METABOLIC, HEARING

[P-64] **Development of the Electronic Tennessee Child Health Profile**
***David Hollar**, University of Tennessee, Graduate School of Medicine*

[P-65] **Development of Toxicogenomic Newborn Screening with DNA Microarray Using Human Umbilical Cords**
***Chisato Mori**, Chiba University, Graduate School of Medicine*

[P-66] **Genotyping of Single Nucleotide Polymorphism (SNPs) Associated with Deafness as an Adjunct to Physiological Screening for Congenital Hearing Loss**
***Karl White,** Utah State University*

[P-67] **Linking Birth Certificate and Newborn Screening Data: Approaches, Results, and Lessons**
***Sherry Spence**, Oregon Department of Human Services*

[P-68] **Surveillance and Long-Term Follow-Up of Infants Identified with Tandem Mass Spectrometry (MS/MS) Detectable Disorders: Interim Progress Report of a Three-Year Cooperative Agreement with the Centers for Disease Control, Idaho, Iowa and Oregon**
***Judi Tuerck**, Oregon Health and Science University*

[P-69] **The Effect of Unsatisfactory Specimens on Newborn Screening**
***Lisa Kalman**, Centers for Disease Control and Prevention*

WOMEN'S HEALTH

[P-70] **Evaluation of the Reproductive Health Surveillance System in Haiyan County, People's Republic of China, 1993-2002**
***Lorraine Yeung**, Centers for Disease Control and Prevention*

[P-71] **More Than 25% of Unborn American Babies May Be At Risk of Neurodevelopmental Deficits from Low Maternal Intake of Iodine During Pregnancy**
***Offie Soldin,** Georgetown University Medical Center*

[P-72] **Thyroid Hormones in Pregnancy and 1-Year Post Partum. Reference Ranges Using Isotope Dilution Tandem Mass Spectrometry: A Longitudinal Study and Comparison with Immunoassays**
***Offie Soldin,** Georgetown University Medical Center*

[P-73] **Using the PPOR Approach to Implement Preconception Health Policies and Programs**
***Jennifer Skala**, CityMatCH*

[P-74] **LIFE LONG HAPPINESS: A Preconception Health Education Project - Helping Women Make Healthy Choices**
***Jean Higgins,** New Mexico Department of Health, Children's Medical Services*

[P-75] **The Impact of Maternal Hypothyroidism during Pregnancy on the Developing Fetus: Considerations for Public Health**
***Micah Milton**, Centers for Disease Control and Prevention*

OTHER

[P-76] **Calculating the Indirect Costs of Birth Defects, Developmental Disabilities, or Disabling Conditions: Productivy Estimates for the United States**
***Scott Grosse**, Centers for Disease Control and Prevention*

[P-77] **Parental Perceptions of Pediatric Care in the Hispanic Population: English vs. Spanish Speaking**
***Mariel Lopez** and **Ruth Perou**, Centers for Disease Control and Prevention*

[P-78] **Public Health Informatics Best Practices: A Practical Approach to Data Modeling and Database Design**
***Thomas Savel**, Centers for Disease Control and Prevention*

[P-79] **SAS Output Delivery System: Part of an Integrated Project Management Approach**
***Clinton Alverson**, NCBDDD, Centers for Disease Control and Prevention*

[P-80] **The Developmental Genome Anatomy Project (DGAP): In Search of Genes Critical for Human Development**
***Janie Lewis**, Morton Laboratory*

[P-81] **NTP Center for the Evaluation of Risks to Human Reproduction: The First Five Years**
***Gloria Jahnke**, Sciences International*

[P-82] **Comparing States Using Survey Data on Health Care Services for Children with Special Health Care Needs**
***Matthew Bramlett**, National Center for Health Statistics*

Symposia

1:30 p.m. – 3:00 p.m. **Part One: Newborn Screening: New Challenges and Opportunities** Ambassador Ballroom

Moderator
Jennifer L. Howse, PhD
President
March of Dimes

Speaker
Rodney Howell, MD
Professor, Department of Pediatrics
The University of Miami School of Medicine

Over a span of 40 years public health newborn screening (NBS) programs have evolved into systems that ensure virtually every infant born in this country receives newborn bloodspot screening and increasingly, newborn hearing screening. More recently, advances in screening technology and treatment options have presented the newborn screening programs with dilemmas and questions. In 2001 the American College of Medical Genetics, under contract to HRSA's Maternal and Child Health Bureau, convened an expert group to review available information on newborn screening and to evaluate current and future practices and methods based upon best scientific evidence and analysis of that information. The findings would create a model decision matrix for changing NBS Program screening panels and outline a uniform panel of conditions for screening. This group's findings will have significant impact on State-based newborn screening specifically and genetic screening generally.

Part Two: Newborn Screening for Intellectual Disabilities Ambassador Ballroom

Moderator
Don Bailey, PhD
Director, FPG Child Development Institute
University of North Carolina at Chapel Hill

Speakers
Steven F. Warren, PhD
Director, Schiefelbush Institute for Lifespan Studies
University of Kansas

Debra Skinner, PhD
Senior Scientist, FPG Child Development Institute
University of North Carolina at Chapel Hill

The Human Genome Project has resulted in the discovery of literally hundreds of genetic causes of intellectual disability, and technological advances mean that soon hundreds of disorders may be screened as cheaply as one. For most forms of intellectual disability there will be no medical treatment, but early intervention and family support could be provided. What are the implications of these challenges for policy and practice?

This symposium addresses these issues in three ways. The first presentation discusses changing criteria for determining disorders to include in newborn screening. A recent evaluation matrix developed by a task force of the American College of Medical Genetics will be described. Fragile X Syndrome will be used as an example of how an intellectual disability could be rated using such a matrix. The second presentation discusses treatment efficacy as a standard for newborn screening, whether this standard has been met for intellectual disabilities, and issues regarding future studies of treatment efficacy. The third presentation examines social science, bioethical, and legal critiques of newborn screening for genetic conditions associated with intellectual disability. Included will be a summary of studies on parents' views of newborn screening and how parent perspectives could be important in making policy decisions.

Symposia

1:30 p.m. – 3:00 p.m. **International Clearinghouse for Birth Defects Monitoring Systems: Past, Present and the Future** Diplomat Room

Moderator
Pierpaolo Mastroiacovo, MD
Professor of Paediatrics, Director of ICBD
International Centre on Birth Defects (ICBD)

Speakers
Lorenzo D. Botto, MD
Medical Epidemiologist
Centers for Disease Control and Prevention

John Harris, MD, MPH
Program Chief
California Birth Defects Monitoring Program

Pierpaolo Mastroiacovo, MD
Professor of Paediatrics, Director of ICBD
International Centre on Birth Defects (ICBD)

Elisabeth Robert Gnansia, MD, PhD
Scientific Director
Institut Européen des Génomutations

Csaba Siffel, MD, PhD
Epidemiologist
Centers for Disease Control and Prevention

The International Clearinghouse for Birth Defects Monitoring Systems was established in 1974. Currently, 40 registries are active members of this worldwide organization covering almost 3.5 million births per year. The three main objectives are basically the same as when the organization was established: 1) Exchange of information on the prevalence of birth defects; 2) Conduct collaborative epidemiologic research; and 3) Provide expert consultation and assistance for existing monitoring systems, investigate outbreaks, and facilitate the establishment of new monitoring systems.

The purpose of this symposium is to present:

a) Examples of geographical variation for selected birth defects;
b) Variations in temporal trends of birth defects, including for some of them the impact of prenatal diagnosis;
c) The creative use of existing registry data to evaluate possible associations between selected birth defects and medications taken during the first trimester of gestation;
d) The recently established International Database on Craniofacial Anomalies, sponsored by WHO, which at present includes case information on about 5.000 cases of Typical Orofacial Clefts from more than 50 registries in 31 countries;
e) Experience and opportunities for public health genetic research in an international setting;
f) Strategies for increased relevance of birth defects monitoring systems in the future.

Symposia

1:30 p.m. – 3:00 p.m. **Part One: The Power of Parents - Public Health Interventions to Promote Child Development and Well-Being** Empire Room

Moderator
Ruth Perou, PhD
Team Lead, Child Development Studies
Centers for Disease Control and Prevention

Speakers
Michelle Gross, PhD
Associate Director for Research, The Debbie Institute
University of Miami

Judy Howard, MD
Professor Emeritus
University of California at Los Angeles (UCLA)

Leila Beckwith, PhD
Professor Emeritus
University of California at Los Angeles (UCLA)

Keith Scott, PhD
Professor, Department of Psychology
University of Miami

The failure of many of America's children to reach their full potential is an issue of major national concern. Parents play a critical role in their children's development, health, and well-being, and are responsible for their children's environment. Children develop within the context of their family and their well-being is affected by the nature of the relationship with their parents. There is growing evidence that parenting interventions may be effective in addressing a myriad of public health concerns. This symposium will discuss the importance of focusing on parents to improve children's outcomes and describe current public health efforts in this area.

Part Two: Transitions and the Medical Home Empire Room

Speakers
Betty Presler, ARNP, PhD
Care Coordinator/Consultant,
Shriners Hospitals for Children/Healthy and Ready to Work National Center

Hatim A. Omar, MD, FAAP
Associate Professor
University of Kentucky, Chandler Medical Center, Kentucky Clinic

In 2002, it was estimated that 6% of children/youth with special health care needs receive guidance and support in transitioning to the adult health care system. With the adult health care system being more fragmented and less interdisciplinary, the ability to provide proficient assistance to youth with special needs transitioning is critical for sustaining quality of care. Provider education around how to assist in the transition process within a medical home, and in particular, communication strategies for enabling such provision of care are essential. This presentation takes a developmental approach to a provider's role in guiding the transition process, along with providing role-playing scenarios that will serve as a forum for illustrating appropriate communication strategies for providers to utilize. Discussion will also promote self-determination within YSHCN and the importance of starting early in transition planning.

Symposia

1:30 p.m. – 3:00 p.m. **Meeting the Challenge: Using Policy to Improve the Public's Health** Palladian Room

Moderator
Pam Dougherty, MA
Program Analyst
Centers for Disease Control and Prevention

Speakers
Emil Wigode
Deputy Director, Federal Affairs
March of Dimes

Denise R. Green, MPH
ORISE Fellow, NCBDDD
Centers for Disease Control and Prevention

Marcus Gaffney, MPH
ORISE Fellow, NCBDDD
Centers for Disease Control and Prevention

Scott Grosse, PhD
Senior Health Economist
Centers for Disease Control and Prevention

Molly E. French, MA
Principal
Potomac Health Consulting

John Kattwinkel, MD
Charles Fuller Professor of Neonatology, Department of Pediatrics
University of Virginia

Ensuring that critical public health research findings result in real benefit to the public's health can be a challenge. Although this challenge can be met in a variety of ways, all too often it is not met at all. Policy development is an important tool for ensuring that public health research findings are put into practice. In this context, policy refers to legislation, regulations, and voluntary practices that influence systems development, organizational change, and individual behavior. Policy development occurs through the advancement of laws (legislation), regulations, and guidelines and through the adoption of voluntary practices (for example, workplace fitness programs).

This symposium describes the relationship between public health research and policy development and includes a discussion of those who are responsible for translating public health research into policies. The interactive panel discussion will include an overview of policy development, along with applied case studies that present different perspectives on the development of laws, regulations, and voluntary practices. Case studies will include the role of state legislation in Early Hearing Detection and Intervention programs, the development of the Children's Health Act of 2000, the effectiveness of folic acid fortification in the prevention of neural tube defects, and screening for kernicterus and developmental disabilities.

Symposia

1:30 p.m. – 3:00 p.m. **The Prevention of Secondary Conditions in People with Disabilities: What Have We Learned in Ten Years** Hampton Room

Moderator
Roberta Carlin, JD, MS
Executive Director
American Association on Health and Disability

Speakers
Donald Lollar, EdD
Senior Research Scientist
Centers for Disease Control and Prevention

Margaret Turk, MD
Professor, Physical Medicine and Rehabilitation
SUNY Upstate Medical University

Catherine Leigh Graham
Rehabilitation Engineer, South Carolina Disability and Health Project
University of South Carolina

Craig Ravesloot, PhD
Associate Research Professor/Research Director, Rural Institute on Disabilities
University of Montana

Susan Kinne, PhD
Research Scientist, Center for Disability Policy and Research
University of Washington

Suzanne McDermott, PhD
Professor, Department of Family and Preventive Medicine
University of South Carolina School of Medicine

Tan Platt, MD
Professor, Department of Family and Preventive Medicine
University of South Carolina School of Medicine

Dorothy E. Nary, MA
Training Director, Research and Training
Center on Independent Living

In 1994, a seminal symposium in the field of prevention of secondary conditions in people with spina bifida and cerebral palsy was convened in Washington, DC. Those conference recommendations have guided the development of initiatives and interventions aimed at reducing the incidence of secondary conditions in people with disabilities over the last 10 years. This current symposia will look at how far we have come, what we have learned and what directions we need to move in to continue the efforts to prevent the incidence of secondary conditions in people with disabilities and reduce health disparities between people with disabilities and the general population. Discussion will focus on identifying effective intervention strategies and the use of health promotion and wellness initiatives and interventions.

Panelists will discuss the progress since the 1994 recommendations in health promotion and wellness initiatives in the areas of emotional health; physical activity and nutrition; achieving and maintaining body systems integrity; data collection on population prevalence and incidence of secondary conditions, in people with disabilities. The symposia will also focus on emerging secondary conditions over the next 10 years.

Symposia

1:30 p.m. – 3:00 p.m. **Information and Resource Centers: A National Approach to Improving the Lives of People with Chronic Conditions and Disabilities** Congressional Room

Moderators
Catherine Lesesne, MA, MPH
Behavioral Scientist
Centers for Disease Control and Prevention

Juliana Cyril, PhD, MPH
Health Scientist
Centers for Disease Control and Prevention

Speakers
Leslie Duncan, MLS
Project Director, National Limb Loss Information Center
Amputee Coalition of America

Karen White, MLS
Director, National Resource Center on AD/HD
Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

Timothy MacGeorge, MSW
Deputy Director, National Resource Center on AD/HD
Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

Joseph Canose, MLS
Director, Christopher and Dana Reeve Paralysis Center
Christopher Reeve Paralysis Foundation

James Rimmer, PhD
Principal Investigator, National Center on Physical Activity and Disability
and Professor, Department of Disability and Human Development
University of Illinois at Chicago

Representatives from the National Limb Loss Information Center, the National Resource Center on AD/HD (Attention-Deficit/Hyperactivity Disorder), the Christopher and Dana Reeve Paralysis Resource Center, and the National Center on Physical Activity and Disability will explain how national resource centers empower and educate people and encourage self-determination through various mechanisms. Methods include dissemination of evidence-based information, call centers, publications, research, and community outreach programs. These representatives will also discuss innovative ways of reaching minority families, collaborating with health care providers, and creating websites specifically for populations with diverse abilities. Each presenter will describe the populations being served and the specific successes and challenges to operating their resource center. Participant discussion will be encouraged and facilitated by National Center on Birth Defects and Developmental Disabilities' (NCBDDD) program staff who work with the centers.

NCBDDD supports these national resource centers as an approach to ensuring that people of different abilities can live their lives to the fullest potential. The resource center model aims not only to directly assist affected individuals and consumers, but also to inform health care providers, allied health care professionals, advocates, and policymakers on important health issues. Specifically, the resource centers are intended to improve the overall quality of life and health care for people with disabilities, disorders, and related secondary conditions by providing valuable health information to them. This symposium will describe the resource centers' approach to health education and information dissemination, and their challenges and successes. Additionally, how to most effectively use this network of centers in support of individuals and families affected by chronic health conditions or disabilities will be discussed.

3:00 p.m. – 3:30 p.m. Break and Refreshments Foyers to Breakout Rooms

Contributed Papers Sessions

3:30 p.m. – 5:00 p.m. **Muscular Dystrophy and Other Single Gene Disorders: Focusing Our Public Health Message** Ambassador Ballroom

Moderator
Christopher Cunniff, MD
Professor of Pediatrics, Pathology and Obstetrics and Gynecology,
Chief, Section of Medical and Molecular Genetics
University of Arizona Health Sciences Center

Speakers
Impact of Prenatal and Newborn Screening on Diagnostic Trends in Cystic Fibrosis—United States, 1996-2002
Shauna Lyn, MD
Epidemic Intelligence Service Officer
Centers for Disease Control and Prevention

Newborn Screening for Duchenne Muscular Dystrophy—Recommendations of an Expert Panel
Katherine Kolor, PhD, MS
ORISE Fellow
Centers for Disease Control and Prevention

Knowledge and Concern about Respiratory Illness in Males with Duchenne Muscular Dystrophy and Their Parents
Christina Trout, MSN, RN
Advanced Practice Nurse, Neuromuscular Program
University of Iowas Hospitals and Clinics, Department of Pediatrics/University of Iowa, College of Nursing

Mortality in Duchenne Muscular Dystrophy: An Analysis of Multiple Cause Mortality Data, 1983 to 1997
Aileen Kenneson, PhD, MS
Epidemiologist
Centers for Disease Control and Prevention

The Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet)
Lisa Miller, MD, MSPH
Director, Disease Control and Environmental Epidemiology Division
Colorado Department of Public Health and Environment

The diagnosis of many genetic conditions is apparent at birth or soon thereafter because they are associated with a specific pattern of birth defects or metabolic disturbances. For disorders such as cystic fibrosis and Duchenne and Becker muscular dystrophy (DBMD) however, the slow development of clinical symptoms may delay diagnosis for years, during which time the child may undergo multiple diagnostic procedures and the family may have other affected children. Early diagnosis and prompt treatment of complications can improve clinical outcome for many of these later onset conditions. The benefits of screening to affected individuals, their families and society as a whole will be discussed, and information from established DBMD screening programs in other countries will be presented. The recommendations of this panel will be used to shape a research agenda for DBMD. The goals, methods and analytic objectives of MD STARNet will be discussed, along with the potential clinical and public health benefits of knowledge gained from this effort.

Contributed Papers Sessions

3:30 p.m. – 5:00 p.m. **Early Hearing Detection and Intervention: Current Status and New Strategies** Diplomat Room

Moderator
Pamela Costa, MA
Health Scientist
Centers for Disease Control and Prevention

Speakers

Efficacy of OAE/ABR Protocol in Identifying Hearing Loss in Newborns
Jean L. Johnson, DrPH
Principal Investigator
University of Hawaii

Karl R. White, PhD
Director, National Center on Hearing Assessment and Management
Utah State University

Birth Score System and Newborn Hearing Screening in West Virginia
Melissa Baker
Epidemiologist
West Virginia Office of Maternal, Child and Family Health

Building an Online Bridge to the World of EHDI: An Overview of the CDC-EHDI State Profile
Rupa Patel
ORISE Fellow
Centers for Disease Control and Prevention

Early Hearing Detection and Intervention (EHDI) Storyboard: An Example of Educational Materials for Families of Infants with Hearing Loss
Krista Biernath, MD
Medical Officer
Centers for Disease Control and Prevention

Audiologists and Early Hearing Detection and Intervention: Surveys from Three States
Beppie Shapiro, PhD
Assistant Professor
University of Hawaii

Evaluation of Early Hearing Detection and Intervention—Michigan, 1998-2002
Darline El Reda, DrPH, MPH
Epidemic Intelligence Service Officer
Michigan Department of Community Health

Hearing loss occurs in approximately 12,000 babies each year (one to three of every 1000 births). An undetected hearing loss during infancy may result in communication, language development, social, emotional, and cognitive delays. Early Hearing Detection and Intervention (EHDI) is a national initiative that supports the early identification of infants and young children with hearing loss through screening, evaluation, and diagnosis, and enrollment into intervention services. The presentations at this session will provide examples of how states have implemented EHDI programs, procedures they use to evaluate their success, and how they seek feed-back and involvement from key partners. Attendees will learn about an online CDC resource (EHDI State Profile) where they can query state EHDI program characteristics. Finally, research results will be presented on the two major screening technologies and implications for screening protocol.

Contributed Papers Sessions

3:30 p.m. – 5:00 p.m. **Fetal Alcohol Syndrome: Marketing Prevention, Changing Behaviors, and Assessing Developmental Outcomes** Empire Room

Moderator
Louise Floyd, RN, DSN
Team Lead, Fetal Syndrome Alcohol Prevention
Centers for Disease Control and Prevention

Speakers
Developmental/Neurological Profile of Infants in de Aar, Northern Cape, South Africa with Special Emphasis on Those with Fetal Alcohol Syndrome
Leigh-Anne Fourie
de Aar Project Coordinator, FAS Prevention Study Team
Foundation for Alcohol Related Research (FARR)

Binge Drinking in the Preconceptional Period and Unintended Pregnancy
Leslie Lipscomb, MPH
Epidemiologist
Centers for Disease Control and Prevention

Competing Discourses of Mothering: Implications for Pregnancy and Alcohol-Related Health Campaigns
Elizabeth Pearce, PhD
Project Manager, Media Effects on Alcohol Consumption Grant, Department of Community and Behavioral Health
University of Iowa

Effect of a Social Marketing Campaign on African-American Women's Knowledge of Fetal Alcohol Syndrome (FAS)
Margaret Ulione, PhD, RN
Vice-Chair and Research Director
St. Louis University, Department of Community and Family Medicine

Fetal Alcohol Syndrome: An Innovative Social Action Model
Teshia Arambula Solomon, PhD
Assistant Professor, School of Public Health
University of Texas Health Science Center at Houston

Fetal alcohol syndrome is a preventable birth defect that results in facial anomalies, growth retardation, and central nervous system problems. FAS can occur among individuals whose mothers drank alcohol while pregnant. The prevention of alcohol use during pregnancy is an important international public health issue. Creative strategies to prevent fetal alcohol syndrome and other adverse birth outcomes are needed to educate women about the risks of drinking alcohol during pregnancy both for their own health and the health of their child.

In this session, speakers will discuss critical issues currently being explored in the FAS research and prevention arenas. The audience will learn about efforts in South Africa to better identify children exposed to alcohol prenatally and determine how this exposure affects their neurodevelopment. Recognizing the role of binge drinking in FAS prevention and in the prevention of unintended pregnancies will also be examined in this session using data from CDC's Pregnancy Risk Assessment Monitoring System. In developing effective prevention strategies, it is critical to understand the values, attitudes, and behaviors of the target population. Several approaches are described that achieve this understanding and use it to inform community-based FAS prevention efforts.

Contributed Papers Sessions

3:30 p.m. – 5:00 p.m. **Early Intervention and Child Health** Executive Room

Moderator
Kristin A. Moore, PhD
President and Senior Scholar
Child Trends

Speakers
Understanding Unintended Pregnancy: Improving Infant Health
Brenda Colley Gilbert, PhD, MSPH
Team Leader
Centers for Disease Control and Prevention

Association Between Maternity Care Coordination Services and Referral to the Child Service Coordination Program Among Infants with Down Syndrome
Cynthia Cassell, MA
Statistician, Department of Maternal and Child Health and the North Carolina Birth Defects Monitoring Program (NCBDMP)
University of North Carolina—Chapel Hill

Mediating Effects of Maternal Interaction on Affect Regulation Among Infants with Prenatal Alcohol Exposure
Nancy Sheehy Handmaker, PhD
Research Assistant Professor, Department of Psychology
University of New Mexico

Framework for Diagnosis and Intervention for Children with Fetal Alcohol Syndrome and Their Families
Jacquelyn Bertrand, PhD
Behavioral Scientist
Centers for Disease Control and Prevention

Effectiveness of Early Intervention with Children Prenatally Exposed to Cocaine: Replication with Multiple Cohorts
Katherine Bono, PhD
Research Director, Linda Ray Intervention Center
University of Miami

The early years of a child's life are very important. During the infant and toddler years, children grow quickly and have so much to learn. Early intervention and child health programs target families with children 3 years old or younger who have demonstrated, or have potential for, developmental delays. This group includes children with known physical, emotional, or mental disabilities that will probably lead to delay in their development, especially in unintended pregnancies where the infants may be at higher risks due to drug and/or alcohol use by the mother. This session will explore understanding unintended pregnancy and will present data that the timely identification of infants with birth defects to specialized programs is critical to their overall health and development. We will also discuss the dangers of alcohol exposure during pregnancy and provide information about interventions appropriate for children with fetal alcohol syndrome (FAS) or other alcohol related disorders. Finally, there will be discussion of children prenatally exposed to cocaine and who are, therefore, at risk for cognitive, language, and behavioral development delays and represent an early identifiable group that may benefit from early intervention services.

Contributed Papers Sessions

3:30 pm - 5:00 pm

Impact of the Environment on the Health of People with Disabilities

Hampton Room

Moderator
Christopher Kochtitzky, MSP
Deputy Director, Division of Human Development and Disability
Centers for Disease Control and Prevention

Speakers

Active Living: How Community Features Can Promote Health for People Who Are Blind or Visually Impaired
Elaine Gerber, PhD
Senior Research Associate
American Foundation for the Blind

Oases in the Food Desert: Working Toward Access to Healthy Food for People with Disabilities
Susan Kinne, PhD
Research Scientist, Center for Disability Policy and Research
University of Washington

Disability and Public Health Project: Creating a Curriculum
Charles Drum, JD, PhD
Director, Center on Community Accessibility
Oregon Health and Science University

Understanding the Contextual Factors that Influence the Presence of Secondary Conditions for People Who Experience Spinal Cord Injuries
Dean Westwood, MSW
Instructor/Senior Research Associate, Oregon Institute on Disability and Development
Oregon Health and Science University

Development of Accessibility Instruments Measuring Fitness and Recreation Environments (AIMFREE) for People with Disabilities
Amy Rauworth, MS
Associate Director of Operations and Exercise Physiology Research, Department of Disability and Human Development
University of Illinois at Chicago

According to the World Health Organization, “In its broadest sense, environmental health comprises those aspects of human health, disease, and injury that are determined or influenced by factors in the environment. This includes the study of both the direct pathological effects of various chemical, physical, and biological agents, as well as the effects on health of the broad physical and social environment, which includes housing, urban development, land-use and transportation, industry, and agriculture.” More specifically, in is consideration of the new companion classification to the ICD, ICF or the International Classification of Functioning Disability and Health, WHO states “A person’s functioning and disability is conceived as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors. Contextual Factors include both personal and environmental factors. The basic construct of the Environmental Factors component is the facilitating or hindering impact of features of the physical, social and attitudinal world.” This session will attempt to examine this dynamic interaction between person and environment and the health consequences that result.

Contributed Papers Sessions

3:30 p.m. – 5:00 p.m. **Evaluating Risk Factors for Birth Defects** Congressional Room

Moderator
Gary Shaw, DrPH
Senior Epidemiologist and Research Director, California Birth Defects Monitoring Program
March of Dimes Birth Defects Foundation

Speakers
The National Smallpox Vaccine in Pregnancy Registry: Update on Women Inadvertently Exposed to Smallpox Vaccine and Their Pregnancy Outcomes
Margaret Ryan, MD, MPH
Director
DoD Center for Deployment Health Research

Placental Glutathione-S-Transferase PI Activity and Genotype in a Population of Hispanic Women
Teresa Dodd-Butera, DABAT, MS, RN
Adjunct Professor of Environmental Health
San Diego State University

New Estimates of the Effect of Prenatal Smoking on the Risk of Heart Defects
Sarah Williamson, MS, MPH
Student in Doctoral Degree Program, Department of Society, Human Development, and Health
Harvard School of Public Health

Gastroschisis in Utah: A Population-Based Study of BMI and Seasonality
Marcia Feldkamp, PA, MSPH
Director, Utah Birth Defect Network
University of Utah Health Sciences Center, Division of Medical Genetics

Periconceptional Dietary Intake of Choline and Betaine and Neural Tube Defects in Offspring
Gary Shaw, DrPH
Senior Epidemiologist and Research Director, California Birth Defects Monitoring Program
March of Dimes Birth Defects Foundation

This dynamic session will present information on issues related to surveillance and on risk factor-birth defect-outcome associations. With respect to surveillance, two papers will be presented. The first will describe the outcomes of pregnancies that were inadvertently exposed to smallpox vaccine. The second paper will characterize the Hispanic population for enzyme activity relevant to detoxification. The remaining three papers in this session present new data on associations between maternal risk factors, including cigarette smoking, body mass index, and methyl-donor nutrients, and birth defects affecting the heart, abdominal wall, and neural tube.

Evening Events

5:00 p.m. - 7:00 p.m.	Ancillary Meeting **National Information and Resource Center Directors Meeting**	Committee Room
7:00 p.m. - 9:00 p.m.	**Reception**	Palladian Room

Program Events
Tuesday, July 27, 2004

6:30 a.m.	– 8:00 a.m.	Networking Breakfast	Ambassador Ballroom
8:00 a.m.	– 9:30 a.m.	Plenary	Regency Ballroom
9:30 a.m.	– 10:00 a.m.	Breaks and Refreshments Exhibits	Regency Ballroom Foyer Blue Room
10:00 a.m.	– 11:30 a.m.	Symposia	See Pages 36-41
11:30 a.m.	– 1:30 p.m.	Awards Program and Luncheon	Regency Ballroom
2:00 p.m.	– 3:30 p.m.	Contributed Papers Sessions	See Pages 42-47
3:30 p.m.	– 4:00 p.m.	Breaks and Refreshments Exhibits	Foyers to Breakout Rooms Blue Room
4:00 p.m.	– 5:30 p.m.	Symposia	See Pages 48-53
7:30 p.m.	– 9:30 p.m.	NCBDDD Strategic Planning Partners Forum	Empire Room

Plenary

8:00 a.m. – 9:30 a.m.

Implications for Advances in Genomics to Public Health Research and Prevention

Regency Ballroom

Moderator
Muin Khoury, MD, PhD
Director, Office of Genomics and Disease Prevention
Centers for Disease Control and Prevention

Presenters

Will Genomics Help Us Navigate the Future?
Alan Guttmacher, MD
Deputy Director, National Human Genome Research Institute and
Director, Office of Policy, Communications and Education
National Institutes of Health

From Biobanks to Public Health?
Bartha Knoppers, MA, LLB, BCL, DLS, PhD
Canada Research Chair in Law and Medicine, Professor at the Faculté de droit and Senior Researcher
Université de Montréal, Center for Public Law (CRDP)

This session will examine the implications of our rapidly expanding knowledge of genetics for public health research and programs. Speakers will address the following questions. What are the health and societal implications of the human genome project? How is this new knowledge best integrated into public health and medical practice? What are the novel public health ethical dilemmas created by the advances in genetics?

Symposia

10:00 a.m. – 11:30 a.m. **Integrating Child Health Information Systems** Ambassador Ballroom

Moderator
David Ross, ScD
Director, Public Health Informatics Institute
The Task Force for Child Survival and Development

Speakers
Deborah Linzer, MS
Senior Public Health Analyst
Health Resources and Services Administration

John Eichwald, MA
Team Lead, Early Hearing Detection and Intervention
Centers for Disease Control and Prevention

Alan R. Hinman, MD, MPH
Principal Investigator, All Kids Count
Task Force for Child Survival and Development

States are under increasing pressure to advance their health information infrastructure to improve public health capacity, effectiveness, efficiency and overall quality of health and healthcare. Although this session will focus on the integration of child health information systems across public and private sectors, the organizational elements essential to successful integration and coordination are applicable to any information systems project, regardless of its focus or scope. This symposium will be relevant to those interested in planning and implementing a health information systems project, including program managers, chief information officers, federal policy and program staff, and public health executives at the federal, state and local levels.

Symposia

10:00 a.m. – 11:30 a.m. **New Concepts in Infectious Causes of Birth Defects and Developmental Disabilities** Diplomat Room

Moderators
Ned Hayes, MD
Medical Epidemiologist
Centers for Disease Control and Prevention

Sonja Rasmussen, MD, MS
Associate Director for Science, Division of Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

Speakers
Mark Abzug, MD
Professor of Pediatrics, Pediatric Infectious Diseases
The Children's Hospital

James Bale, MD
Professor and Vice Chair, Department of Pediatrics
University of Utah and Primary Children's Medical Center

Daniel O'Leary, DVM
Medical Epidemiologist
Centers for Disease Control and Prevention

Gary Shaw, DrPH
Senior Epidemiologist and Research Director, California Birth Defects Monitoring Program
March of Dimes Birth Defects Foundation

The emergence of new infectious agents in North America and of new techniques for evaluating etiologies of birth defects and disabilities have provoked important questions regarding possible teratogenic effects of maternal infections. West Nile virus has been shown to cause congenital infection with possibly severe clinical consequences. The understanding of the impact of CMV infection on congenital deafness continues to evolve. New strategies are needed and being proposed to further evaluate the effects of maternal infections on birth outcomes. This session will present new information on the impact of infectious agents on birth defects and developmental disabilities and will explore new strategies to further evaluate this evolving public health problem.

The session will begin with an overview of the clinical approach to evaluating infectious diseases as a cause of birth defects and developmental disabilities. This will be followed by presentations updating recent information on the role of cytomegalovirus as a cause of hearing deficits, the risks associated with West Nile virus infection during pregnancy, and a new program for evaluating the role of infectious diseases as causes of birth defects in a state birth defect monitoring program. Time will be available for brief discussion of each specific topic as well as the central theme regarding the epidemiologic approach to evaluating infectious diseases as etiologic agents of birth defects and developmental disabilities.

Symposia

10:00 a.m. – 11:30 a.m. **Creating Effective Communication Campaigns: Lessons from the Field** Empire Room

Moderator
Mary Kate Weber, MPH
Behavioral Scientist
Centers for Disease Control and Prevention

Speakers
Deborah C. Glick, ScD
Professor, School of Public Health, Health and Media Research Group
University of California—Los Angeles (UCLA)

Mark Mengel, MD, MPH
Professor and Chair
St. Louis University

Elizabeth Pearce, MA, PhD
Manager, Media Effects on Alcohol Consumption Grant
University of Iowa, Department of Community and Behavioral Health

Maternal alcohol use during pregnancy can result in prenatal alcohol exposure, effects of which range from subtle to severe. Three CDC-funded, university based projects have developed, implemented and evaluated targeted media campaigns designed with local participation to raise awareness about the dangers of drinking during pregnancy and prevent prenatal alcohol exposure. Techniques used include narrowcasting campaigns (UCLA); a comprehensive multimedia campaign approach (St. Louis University); and a campaign seeking to promote dialogue within social networks that uses both broad-based and localized media (University of Iowa).

This panel discussion will highlight these unique projects and present effective strategies and lessons learned on how to conduct community-based health communication campaigns. Particular emphasis will be placed on the need for targeted campaigns as opposed to broad mass media campaigns. After an initial overview of each project, the panel will engage the audience in a dialogue discussing topics that include conducting formative research, developing campaign materials, assessing campaign process and impact measures, and working with community partners and creative agencies.

Symposia

10:00 a.m. – 11:30 a.m. **The Health of People with Intellectual Disabilities: A Multidimensional Approach to Understanding and Addressing the Problem** Palladian Room

Moderator
Mary C. Cerreto, PhD
Associate Professor of Family Medicine and Director, Center on Self-Determination and Health
Boston University Medical Center

Speakers
David L. Coulter, MD
Associate Professor of Neurology
Harvard Medical School

Stephen Corbin, DDS, MPH
Dean
Special Olympics University

Gary N. Siperstein, PhD
Director, Center for Social Development and Education
University of Massachusetts at Boston

James H. Rimmer, PhD
Principal Investigator, National Center on Physical Activity and Disability and Professor, Department of Disability and Human Development
University of Illinois at Chicago

The report of the US Surgeon General's Conference on Health Disparities and Mental Retardation documented that people with intellectual disabilities are at greater general risk for poor health and at specific risk for certain health conditions. A variety of activities has ensued since the Surgeon General's conference. This symposium will report on several of these activities and will indicate areas in which future efforts are needed.

Symposia

10:00 a.m. – 11:30 a.m. **Caregiving in America as an Emerging Public Health Issue: Surveillance and Response by the Nation's Public Health System**

Hampton Room

Moderator
Ronda C. Talley, PhD, MPH
Executive Director and Professor
Rosalynn Carter Institute for Caregiving

Speakers
John Crews, PhD
Health Scientist
Centers for Disease Control and Prevention

Mindy L. Aisen, MD
Director, Technology Transfer Program
Department of Veteran's Affairs

Gail Hunt
Executive Director, Youth Careers in America
National Alliance for Caregivers

Jean Silvernail, PhD
Program Analyst, Educational Opportunites Directorate
Department of Defense

Jennifer Zeitzer
Associate Director
Alzheimer's Disease and Related Disorder Association

In recent years, the needs of caregivers in America have become increasingly recognized as an emerging public health issue. While more and better data are available on the numbers of caregivers and their needs as well as the quantity and quality of services available to address those needs, surveillance efforts have been sporadic and fragmented. In addition, little attention has been paid to the public health system's role in supporting caregivers. The symposium will present data on caregivers as vital consumers of public health services and suggest ways the public health system can better address their needs at the local, state, and national levels.

Symposia

10:00 a.m. – 11:30 a.m. **Advancing Public Health Priorities Through Advocacy** Congressional Room

Moderator
Dave Zook, JD
Managing Partner
B&D Sagamore

Speakers
Debra Lappin, JD
Senior Advisor
B&D Sagamore

Keith Mueller, MA, PhD
Director, Center for Rural Health Research
University of Nebraska Medical Center

Audrey Young
Principal
B&D Quorum

Deborah Dietrich, MA
Director, Center for Policy and Advocacy
Association of Maternal and Child Health Programs

Advocacy has become an effective and important tool for influencing public health policy and program implementation at the local, state, and federal levels. However, key strategies and tactics must be properly utilized in order to produce effective outcomes for advancing your community's policy agenda. The purpose of this symposium is to provide organizations with a sound understanding and effective tools for communicating research and public health priorities to policy stakeholders and decision makers.

11:30 a.m. – 1:30 p.m. **Awards Program and Luncheon** Regency Ballroom

Contributed Papers Sessions

2:00 p.m. – 3:30 p.m. **New Horizons for PreNatal and NeoNatal Screening** Ambassador Ballroom

Moderator
Elizabeth Thomson, MS, RN
Program Director, The Ethical, Legal and Social Implications Program
National Human Genome Research Institute

Speakers
Expanded Newborn Screening: The Mississippi Experience
Daniel Bender, MHS
Office Director, Office of Health Services
Mississippi State Department of Health

Neonatal Screening Program by Tandem Mass Spectrometry in a Mexican Population
Laura E. Martinez, MD, MSc
Chairman, Department of Genetics
Medical School University of Nuevo Leon

First PAGE: A Strategy for Screening for Birth Defects and Genetic Disorders in a Primary Prenatal Care Setting
Edward M. Kloza, MS
Director, Prenatal Screening Coordinator
Foundation for Blood Research

Attitudes Toward Prenatal Testing Among Texas Women
Amy Peterson Case, MAHS
Program Specialist
Texas Department of Health

Prevalence of 2-Methylbutyrl-COA Dehydrogenase Deficiency (MBADD) Identified by Newborn Screening in the Hmong-American Population of Wisconsin
Maureen Durkin, PhD, DrPH
Associate Professor
University of Wisconsin

The opportunity for the early identification (prenatal or newborn) of genetic diseases has been magnified by developments in the field of molecular genetics and various technologies (e.g., Tandem Mass Spectrometry and DNA Chip analysis) available to identify multiple disorders from a small biologic specimen (e.g., single newborn blood). With these opportunities comes the public health responsibilities to implement population-wide screening using scientific rigor to assure that the net benefit on a population level exceeds potential risks and harms associated with screening. This session will examine a number of perspectives in prenatal and newborn screening including the experience of one state health department, the family perspective; the potential application to primary care; and a very interesting observation of a rare disorder found more frequently in an ethnic minority population.

Contributed Papers Sessions

2:00 p.m. – 3:30 p.m. **Risk Factors for Autism Spectrum Disorders** Diplomat Room

Moderator
Lisa Croen, PhD
Perinatal Epidemiologist, Research Scientist
Kaiser Permanente Division of Research

Speakers
Investigating Linkage of Autism Spectrum Disorder Surveillance Data to Hazardous Air Pollutant Data
Gayle Windham, PhD
Epidemiologist
California Department of Health Services

Using Geographic Information Systems to Link Data from the South Carolina Autism and Developmental Disabilities Monitoring Network with Available Environmental Data
Lydia Buxbaum King, PhD
Researcher
Medical University of South Carolina

MTHFR Polymorphism, Epigenetics, and Risk for Autism
M. Daniele Fallin, PhD
Assistant Professor
Johns Hopkins Bloomberg School of Public Health

Maternal Autoimmune and Allergic Diseases and Childhood Autism
Lisa Croen, PhD
Perinatal Epidemiologist, Research Scientist
Kaiser Permanente Division of Research

This session will explore the role of both genetic and non-genetic factors in the etiology of autism spectrum disorders. The session will commence with two presentations describing studies investigating toxic chemical exposures and their association with autism spectrum disorders. Both studies utilize data from existing autism surveillance systems and various environmental databases. The third presentation will address the impact of MTHFR polymorphism and epigenetics on the risk of autism. Data on the association between maternal autoimmune diseases, asthma and allergies during pregnancy and childhood autism will be presented by the final speaker.

Contributed Papers Sessions

2:00 p.m. – 3:30 p.m. **Folic Acid Promotion: Modifying Behaviors in Special Populations and Assessing the Effectiveness of Interventions** Empire Room

Moderator
Jaime Frias, MD
Professor of Pediatrics
University of South Florida, Department of Pediatrics

Speakers
Prevalence of Multivitamin Use—New Data from the Pregnancy Risk Assessment Monitoring System (PRAMS), 2000
Letitia M. Williams, MPH
Epidemiologist
Centers for Disease Control and Prevention

Evidence on Effectiveness of Folic Acid Fortification: Results from a Systematic Review for the Guide to Community Preventive Services
David P. Hopkins, MD, MPH
Scientist
Centers for Disease Control and Prevention

Improving Preconceptional Folic Acid Intake Among College-Aged Women
Heidi V. Krowchuk, BSN, MS, PhD
Associate Professor
The University of North Carolina at Greensboro

Spanish-Language Folic Acid Media Campaign—Increasing Knowledge and Changing Behavior Among Hispanic Women of Childbearing Age
Alina L. Flores, MPH, CHES
Health Education Specialist
Centers for Disease Prevention and Control

Health Care Professionals Awareness and Practics Regarding Folic Acid
Stephen M. Abelman, MBA
Manager, Alliance Development, National Education Initiatives
March of Dimes

Research has shown that daily folic acid consumption can help reduce a woman's risk for having a pregnancy affected by a neural tube defect. This session will review how folic acid fortification, education and promotion programs have impacted levels of folic acid awareness, knowledge, and consumption among a variety of populations. This session will also review health care provider practices related to folic acid education and promotion, as well as identify educational opportunities to reach underserved populations.

Contributed Papers Sessions

2:00 p.m. – 3:30 p.m. **Health Promotion and Access to Care for People with Disabilities** Palladian Room

Moderators
JoAnn M. Thierry, MS, MSW
Behavioral Scientist
Centers for Disease Control and Prevention

Speakers
Missed Appointment Parameters Among Children and Adults with Disabilities
Patricia M. Sullivan, PhD
Professor of Neurology and Psychology and Director, Center for the Study of Children's Issues
Creighton University School of Medicine

Improving Access to Breast Cancer Screening for Women with Physical Disabilities
JoAnn M. Thierry, MS, MSW
Behavioral Scientist
Centers for Disease Control and Prevention

Designing Community-Based Strategies to Improve Primary Prevention for People with Physical Disabilities in Virginia: Focus Group Findings
Thilo Kroll, PhD
Senior Research Associate, Center for Health and Disability Research
National Rehabilitation Hospital

Finding the Needle in the Haystack: Using a Touch Screen Computer System to Collect Low Base Rate Healthcare Utilization Information
Craig Ravesloot, PhD
Associate Research Professor/Research Director, Rural Institute on Disabilities
University of Montana

This panel will explore the barriers to health care frequently experienced by children and adults with disabilities. Various strategies for improving access to health care services will be highlighted. Implications for public health practice and research will be discussed.

Contributed Papers Sessions

2:00 p.m. – 3:30 p.m. **Health Status and Quality of Life Among Persons with Disabilities** Hampton Room

Moderator
Charles E. Drum, JD, PhD
Director, Center on Community Accessibility
Oregon Health and Science University

Speakers
Adverse Health Behaviors and Chronic Conditions in Adults with Disabilities
Gwyn Jones, PhD, MSW
Senior Research Associate, Center for Health and Disability Research
National Rehabilitation Hospital

Smoking Status and Quality of Life: A Longitudinal Study Among Adults with Disabilities
Monica Mitra, PhD
Disability Research Consultant
Massachusetts Department of Public Health

Increased Injury Risk Among People with Disabilities
Huiyun Xiang, MD, PhD
Assistant Professor, College of Medicine and School of Public Health
The Ohio State University

Obesity, Quality of Life and Disability Among Youth: A Report from the Washington State Healthy Youth Survey 2002
Tari Topolski, PhD
Research Scientist/Affiliate Assistant Professor
Center for Disability Policy and Research, Seattle Quality of Life Group

Preference Ratings for Health and Disability States are Different for People with Disabilities Compared to the General Population
Elena Andresen, MA, PhD
Professor and Director, Epidemiology Division
Saint Louis University School of Public Health

Health status is one of the basic elements in experiencing a quality life, being self-sufficient, and participating fully in society. The number of people with disabilities is significant: the U.S. Census Bureau estimates that people with disabilities make up approximately 20% of the population or nearly 49.7 million Americans, while other population estimates are even higher. Yet, a number of studies have found that people with disabilities do not have a comparable health status, have a thinner margin of health, and are at greater risk for and generally experience more secondary conditions related to their disability than the non-disabled population.

This session will focus on several studies examining contributors to the health of adults with disabilities (including participation in health risk behaviors such as smoking, drinking, obesity, or lack of physical activity and injury as a secondary condition), as well as health indicators for youth with disabilities. In addition, the session will discuss the evaluation of health states by samples of people with and without disabilities.

Contributed Papers Sessions

2:00 p.m. – 3:30 p.m. **Birth Defects Surveillance: Improving Methods and Use of Data** Congressional Room

Moderator
Marcia Feldkamp, PA, MSPH
Director, Utah Birth Defect Network
University of Utah, Health Sciences Center, Division of Medical Genetics

Speakers

Development of Indiana Birth Defects Surveillance System Educational Program for Hospital Staff at Birthing Hospitals in Indiana
Krysta S. Barton
Student/Genomics Program Consultant
University of Medicine and Dentistry School of Public Health/Indiana State Department of Health

Results of Neural Tube Defects Case Ascertainment Process Combining Vital Records Datasets and Birth Defects Surveillance Data, for Years 1996 through 2001, in Puerto Rico
Elia M. Correa, RN, MPH
Coordinator of Folic Acid Campaign and Birth Defects Surveillance System
Puerto Rico Department of Health

Multi-Center Study for Birth Defects Monitoring Systems in Korea
Jae-Hyug Yang, MD, PhD
Associate Professor and Director, Department of Obstetrics and Gynecology
Samsung Cheil Hospital, Sungkyunkwan University, School of Medicine

Congenital Heart Defects in Utah: Type of Pregnancy Outcome and Timing of Diagnosis Impact Completeness and Reporting
Lynne MacLeod, MStat
Surveillance Project Coordinator, Utah Birth Defect Network
Utah Department of Health

Omphalocele and Gastroschisis: Black-White Disparity in Infant Survival
Hamisu Salihu, MD, PhD
Assistant Professor, Department of Maternal and Child Health
University of Alabama at Birmingham

This session illustrates the importance of evaluating surveillance methods in case ascertainment and utilization of the data collected. Specifically, the first three papers will present mechanisms utilized to identify and enhance case ascertainment for surveillance systems. The fourth paper demonstrates the need for multiple case ascertainment sources to identify all congenital heart defects in a surveillance system. The final paper demonstrates a valuable use of data collected, describing race differences occurring in abdominal wall defects.

3:30 p.m. – 4:00 p.m. Break and Refreshments Foyers to Breakout Rooms
Exhibits Blue Room

Symposia

4:00 p.m – 5:30 p.m. **Improving the Identification of Children with Developmental Disabilities (Including Autism Spectrum Disorders): Models for Early Screening** Ambassador Ballroom

Moderator
Margaret Dunkle
Senior Fellow
The George Washington University School of Public Health and Health Science

Speakers
Jennifer Pinto-Martin, MPH, PhD
Associate Professor
University of Pennsylvania, Center for Autism and Developmental Disabilities Research and Epidemiology

Margaret Souders, MSN, RN, CRNP
Pediatric Nurse Practitioner
Children's Seashore House

Marian F. Earls, MD, MTS
Medical Director and Developmental and Behavioral Pediatrician
Guilford Child Health, Inc.

Rebecca Landa, PhD
Director, Center for Autism and Related Disorders/Associate Professor, Psychiatry
Kennedy Krieger Institute, Johns Hopkins School of Medicine

Cynthia Landes, MPH, MA
Coordinator Community Child Health Programs
Cedar Sinai Medical Center

Nancy Wiseman
President and Founder
First Signs

Through the use of two-stage screening strategies, research studies have demonstrated that autism spectrum disorders (ASD) and other developmental disabilities (DD) can now be reliably and validly detected in children as young as 18 months. Screening and diagnostic practices in the medical and educational arena lag far behind clinical research, however, with the average age of diagnosis reported as 3-6 years of age. This symposium will present several models of early screening for ASD/DD and discuss the pros and cons of the different strategies.

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4:00 p.m. – 5:30 p.m. **Challenges and Opportunities in Developing an Integrated State MCH Surveillance System: the Role of Birth Defects Surveillance** Diplomat Room

Moderator
David Ross, ScD
Director of Public Health Informatics Institute
The Task Force for Child Survival and Development

Speakers
David Ross, ScD
Director of Public Health Informatics Institute
The Task Force for Child Survival and Development

Deneen Long-White
Chief, Data Collection and Analysis Division
DC Department of Health, Maternal and Family Health Administration

Samara Viner-Brown, MS
Chief of Data and Evaluation
Rhode Island Department of Health

April Montgomery, MHA
Prevention Projects Coordinator, Colorado Responds to Children with Special Needs
Colorado Department of Public Health and Environment

As state public health agencies effectively and efficiently develop their capability to monitor health status to identify maternal and child health (MCH) problems, more agencies are looking at an integrated approach to conducting MCH surveillance. This integration may occur at multiple levels: data collection system, data integration, database linkage, information assimilation and distribution, program planning and implementation, referral and follow-up services, etc. State public health agencies currently function at different levels and are approaching the solutions from different perspectives. Birth defects surveillance is an essential component. This session will feature three state programs and their approaches.

Symposia

4:00 p.m. – 5:30 p.m. **Over-the-Counter Medication Use in Pregnancy** Empire Room

Moderator
Martha Werler, ScD, MPH
Epidemiologist, Associate Professor, Slone Epidemiology Center
Boston University

Speakers
Allen A. Mitchell, MD
Professor and Director of Slone Epidemiology Center
Boston University

Sonia Hernandez-Diaz, MD, DrPH
Associate Professor of Epidemiology, Slone Epidemiology Center
Boston University

Martha Werler, ScD, MPH
Epidemiologist, Associate Professor, Slone Epidemiology Center
Boston University

Bridget Mosley, MPH
Epidemiologist
Arkansas Center for Birth Defects Research and Prevention

Jennita Reefhuis, MSc, PhD
Epidemiologist
Centers for Disease Control and Prevention

The most commonly taken medications in pregnancy are sold over-the-counter, and frequently involve cold and analgesic products. Despite this, remarkably little attention has been focused on the fetal risks and safety of these drugs. This symposium will explore relevant public health and research issues surrounding OTC drug use in pregnancy. We will begin by summarizing the limited sources of information on OTC medication use in pregnancy. Various approaches will be described on how to most effectively study OTC medications in pregnancy. Methodologic issues that pertain specifically to collecting information on OTC medication use will be discussed. Patterns of use in pregnancy will be presented, including secular and geographic trends, based on data from two large case-control studies. The issues raised in these first presentations will then be put into context in the next presentations, which focus on specific medications in relation to birth defect risks. Recent findings will be presented on analgesic use in relation to muscular VSDs; the antihistamine, loratadine, in relation to hypospadias; and vasoactive medications (aspirin, ibuprofen, and pseudoephedrine) in relation to birth defects that can arise from vascular disruption.

Symposia

4:00 p.m. – 5:30 p.m. **Reducing Secondary Conditions Among People with Spina Bifida** Palladian Room

Moderator
Ethan S. Long, PhD
Project Director
Association of University Centers on Disabilities

Speakers
Cindy Brownstein
Chief Executive Officer
Spina Bifida Association of America

Timothy J. Brei, MD
Associate Clinical Professor/Director, Spina Bifida Program
Indiana University School of Medicine

Tari Topolski, PhD
Research Scientist/Affiliate Assistant Professor, Center for Disability Policy and Research
Seattle Quality of Life Group

Brian J. Dudgeon, PhD, OTR
Assistant Professor
University of Washington

Despite being one of the most frequently occurring permanently disabling birth defects, limited research exists examining the onset and course of conditions secondary or otherwise related to spina bifida. Recent collaborative efforts between researchers, the advocacy community, and the federal government have led to the development of a national research agenda to address quality of life factors impacting individuals with spina bifida. In this symposium, the findings from a recent conference designed to identify the state of evidence-based practice relating to spina bifida and secondary conditions will be described. In addition, preliminary findings from three projects examining various factors that impact secondary conditions will be described.

Symposia

4:00 p.m. – 5:30 p.m. **A Model for Regional Systems of Care to Promote Health and Well-Being for Persons with Rare Genetic Disorders** Hampton Room

Moderator
Judith R. Baker, MHSA
Region IX Coordinator
Federal Hemophilia Treatment Centers/Region IX

Speakers
Sally O. Crudder, RN
Acting Director, Division of Hereditary Blood Disorders
Centers for Disease Control and Prevention

Brenda Riske, MSN, MBA, MPA
Region VIII Coordinator
Mountain States Regional Hemophilia Treatment Centers

Judith R. Baker, MHSA
Region IX Coordinator
Federal Hemophilia Treatment Centers/Region IX

Val Bias
Past President
National Hemophilia Foundation/Compass Non-Profit Consulting Services

Anne Forsberg, MS, MPH
Region I Coordinator
Federal Hemophilia Treatment Centers/Region I

Providing cost effective services to geographically dispersed individuals with rare and/or under recognized genetic disorders throughout the country poses major challenges to the U.S. health care system. In the 1970's the National Hemophilia Program funded through MCHB and CDC created a model of 12 regional networks that have evolved to offer comprehensive, multidisciplinary, specialized diagnostic and treatment services to persons with a variety of rare and der-diagnosed inherited bleeding disorders. Regional networks of 130+ hospital based specialty centers now provide multidisciplinary health and medical care; conduct patient and clinical education and outreach; perform prevention research, complications surveillance, and clinical trials; monitor and engage in State and Federal policy; and collaborate with consumer advocacy agencies in many of these activities. CDC data demonstrates that care obtained via the Regional network increases lifespan, and decreases morbidity and costs.

To maximize your strength in the State and Federal health care and research arenas, rare disorder clinicians and patient advocates would benefit by collaborating and organizing into regional networks. This session will describe this decades old successful model which has weathered the HIV and Hepatitis C crises, created the largest hemophilia database in the world, built specialty teams from Guam to Alaska – Puerto Rico to Maine, and has begun to focus on prevalent but under-recognized women's bleeding disorders.

Symposia

4:00 p.m. – 5:30 p.m. **From Grassroots to the Steps of the Supreme Court: Developing and Implementing Disability Policy at the Community, State and National Level** Congressional Room

Moderator
Juliana Cyril, MPH, PhD
Health Scientist
Centers for Disease Control and Prevention

Speakers
Lesa Barnes, MA
Project Coordinator
Olympic Area Agency on Aging, Disability Awareness, Surveillance, and Health Promotion Project

Christine Fortunato, MA
Community Advocacy Specialist, Office of Protection and Advocacy for Persons with Disabilities
State of Connecticut

Jonas Schwartz
Manager of Policy Services
The Disability Policy Consortium

Henry Claypool
Co-Director
Advancing Independence Modernizing Medicare and Medicaid

Graham Hill
Counsel, Committee on Transportation and Infrastructure/Member
U.S. House of Representatives/National Council on Disability

Major pieces of federal legislation, such as the Americans with Disabilities Act and the Olmsted Decision, are familiar to many seeking to ensure the rights and quality of life of people with disabilities. However, important activities at the community and state levels often form the backdrop and act as the catalyst for political and legislative action at the federal level. Representatives from communities, states, national organizations and the federal government will discuss current legislative activities related to disability and health. Discussion will focus on how activities at each level help inform and sustain the legislative process.

Evening Events

7:30 p.m. - 9:30 p.m.	**NCBDDD Strategic Planning Partners Forum**	Empire Room

Program Events
Wednesday, July 28, 2004

7:30 a.m. – 8:30 a.m.	Continental Breakfast	Regency Ballroom Foyer
8:30 a.m. – 10:00 a.m.	Symposia	See Pages 57–58
8:30 a.m. – 10:00 a.m.	Contributed Papers Sessions	See Pages 59–62
10:00 a.m. – 10:30 a.m.	Breaks and Refreshments	Regency Ballroom Foyer
10:30 a.m. – 12:00 p.m.	Closing Session	Regency Ballroom
1:00 p.m. – 9:30 p.m.	Ancillary Meetings	See Page 64

- **National Council on Folic Acid Meeting**
- **Early Hearing Detection and Intervention (EHDI) Federal Interagency Advisory Committee Meeting**
- **NBDPN Executive Meeting**
- **Disability and Health State Grantees Meeting**
- **Autism and Developmental Disabilities Monitoring (ADDM) Network and Centers for Autism and Developmental Disabilities Research Epidemiology (CADDRE) Surveillance Meeting**

Symposia

8:30 a.m. – 10:00 a.m. **Preconception Care: Missed Prevention Opportunity** Empire Room

Moderator
José F. Cordero, MD, MPH
Director, National Center on Birth Defects
and Developmental Disabilities
Centers for Disease Control and Prevention

Speakers
Janis Biermann, MS
Vice President Education Health Promotions
March of Dimes

Michele Curtis, MD
Obstetrician
American College of Obstetricians and Gynecologists

Melissa McDiarmid, MD, MPH
Professor of Medicine
University of Maryland School of Medicine

Carol Brady
Director
Northeast Florida Healthy Start Coalition

Kent Burk, MD
Obstetrician
Mercy St. John's Health System

Mary Beth Hasselquist, MD
Obstetrician
Group Health Cooperative of Puget Sound

A strong evidence-base supports many components of preconception care recommended in clinical practice guidelines. Preconception care, care that must be initiated before pregnancy, can reduce the prevalence of targeted risk factors known to be associated with adverse perinatal outcomes — as well as long term women's health outcomes. The fact that these targeted risk factors occur today in substantial prevalence is an indication of poor access to effective care. Public health has the responsibility to provide access to proven interventions to those who can benefit: a group, in this case, comprised of women (or couples) who plan to become pregnant.

Representatives from the March of Dimes (MOD), and the American College of Obstetricians and Gynecologists (ACOG) will discuss preconception care and their organizations' related activities. Presentations on challenges to improve access to care and support information (including environmental and occupational teratogens) will be made. In the final segment there will be a discussion of practical applications by panel members representing private practice, managed care, and a local public health coalition.

Symposia

8:30 a.m. – 10:00 a.m.

Living Well with a Disability: Development, Implementation and Evaluation of a Nationally Recognized Health Promotion Intervention for Adults with Disabilities

Ambassador Ballroom

Moderator
Craig Ravesloot, PhD
Associate Research Professor/Research Director, Rural Institute on Disabilities
University of Montana

Speakers
Tom Seekins, PhD
Associate Director, Rural Institute on Disabilities
University of Montana

Craig Ravesloot, PhD
Associate Research Professor/Research Director, Rural Institute on Disabilities
University of Montana

Dorothy E. Nary, MA
Training Director, Research and Training Center on Independent Living
University of Kansas

Scott Lindgren, PhD
Professor of Pediatrics, Center for Disabilities and Development
University of Iowa

Anthony G. Cahill, MAT, MPIA, PhD
Senior Research Scientist and Head, Disability and Health Policy Unit
University of New Mexico School of Medicine

Reducing the incidence and severity of secondary conditions experienced by people with disabilities has become an important public health initiative. Researchers have reported that the Living Well with a Disability curriculum is a cost-effective intervention for reducing the incidence and severity of secondary conditions. Since then, the Living Well program has been implemented by four State Health Departments funded by the CDC state capacity building program. Through this process of intervention development, implementation and evaluation, many lessons have been learned about providing public health tools to the disability community.

Contributed Papers Sessions

8:30 a.m. – 10:00 a.m.

Autism Surveillance: Improving Methodology and Use of Data

Diplomat Room

Moderator
Walter Zahorodny, PhD
Director, New Jersey Autism Study
New Jersey Medical School

Speakers

Methodology for Multiple Source, Population-Based Surveillance of the Autism Spectrum Disorders (ASDs) in the United States ADDM CADDRE Network
Catherine Rice, PhD
Behavioral Scientist
Centers for Disease Control and Prevention

Modeling Clinical Outcomes of Autistic Spectrum Disorders
James Coplan, MD
Clinical Associate Professor of Pediatrics
University of Pennsylvania School of Medicine

Differentiating Between Autism Spectrum Disorders and Other Developmental Disabilities Using the Modified Checklist for Autism in Toddlers (M-CHAT)
Pamela Dixon, MA
Graduate Student, Department of Psychology
University of Connecticut

Investigating Developmental Delays Study: Comparison of SCQ and PDDST
Craig Newschaffer, PhD, MS
Associate Professor of Epidemiology and Mental Health
Johns Hopkins Bloomberg School of Public Health

PDQ-1 and ABC as Autism Screeners
Walter Zahorodny, PhD
Director, New Jersey Autism Study
New Jersey Medical School

The goal of this session is to provide information regarding research methods that have been used to identify and elaborate characteristics of developmental disabilities. The models presented outline different methods of data collection being utilized in distinctive areas of this research field. The information presented seeks to foster methodologies for the enhancement of developmental disabilities diagnostics and research.

Contributed Papers Sessions

8:30 a.m. – 10:00 a.m. **Children with Disabilities** Palladian Room

Moderator
Rune Simeonsson, PhD, MSPH
Professor of Education, Research Professor of Psychology
FPG Child Development Institute, University of North Carolina at Chapel Hill

Speakers
Physical and Psychosocial Health for Children with Spina Bifida
Kimberlea Hauser, MBA
Associate in Pediatrics
University of South Florida

Adolescent Knowledge and Health Practices in the U.S. Hemophilia Population: National Hemophilia Foundation Baseline Study and Adolescent Health Campaign
Ann-Marie Nazzaro, PhD
Director of Education
National Hemophilia Foundation

The Acquisition of Adult Social Roles Among Young Adults with Developmental Disabilities
Kim Van Naarden Braun, PhD
Epidemiologist, Developmental Disabilities Team
Battelle Memorial Institute (Contractor for Centers for Disease Control and Prevention)

FAMILY MATTERS: Using Bright Futures to Promote Health and Wellness for Children with Disabilities
Barbara Popper, MEd, IBCLC
Project Director
Family Voices at the Federation for Children with Special Needs

Medical Home Implementation through Community-Based, Primary Care Practices: Moving to the Next Level
Colleen A. Kraft, MD
Pediatrician
Richmond Pediatric Associates, Inc.

The papers in this session focus on (1) health characteristics and practices of children and youth with disabilities and special health care needs; and (2) issues related to the provision of health care services for them and their families. Studies of children and youth with spina bifida, hemophilia and developmental disabilities provide descriptions of health impairments and complications unique to each group. Findings from these studies indicate that children and youth with disabilities do experience activity limitations and restrictions in participation associated with their primary condition affecting physical health and psychological well-being. The improvement of health behavior and practices of children with disabilities and special health care needs is explored in two related presentations involving the role of families (Bright Futures) and implementation of the Medical Home concept. Collectively, these presentations provide evidence for the provision of family-centered information and support and access to comprehensive care as the basis for promoting children's health and wellness and contribute to a public health agenda for children and youth with disabilities and chronic conditions.

Contributed Papers Sessions

8:30 a.m. – 10:00 a.m. **Evaluating Risk Factors for Birth Defects: Medication and Supplement Use** Congressional Room

Moderator
Allen A. Mitchell, MD
Director, Slone Epidemiology Center
Boston University

Speakers
Periconceptional Exposure to Oral Contraceptives and the Risk of Neural Tube Defects
Sonia Hernandez-Diaz, MD, DrPH
Associate Professor of Epidemiology
Slone Epidemiology Center at Boston University

Hypospadias and Maternal Intake of Progestins and Oral Contraceptives
Suzan L. Carmichael, PhD
Epidemiologist
California Birth Defects Monitoring Program

Loratadine (Claritin®) and Hypospadias, Data from the National Birth Defects Prevention Study, U.S.A. 1997–2000
Jennita Reefhuis, PhD
Epidemiologist
Centers for Disease Control and Prevention

Medication Use in Pregnancy: 1976–2000
Allen A. Mitchell, MD
Professor, Director of Slone Epidemiology Center
Boston University

Herbal Use in Pregnancy: Results from Two Studies
Carol Louik, ScD
Assistant Professor, Slone Epidemiology Center
Boston University

It is widely known that medications taken in pregnancy can cause birth defects in the exposed offspring, but little is known about the potential teratogenicity of the wide range of medicines taken by pregnant women. This session will begin by focusing on analyses that explore the role of selected drugs in relation to selected birth defects, including oral contraceptives in relation to neural tube defects and hypospadias and loratadine in relation to hypospadias. To help direct further research inquiries, the session will then identify the prescription drugs, OTC products, and herbal remedies that are most commonly used in pregnancy.

Contributed Papers Sessions

8:30 a.m. – 10:00 a.m. **Health Communications: Improving Identification and Care through Education and Training** Hampton Room

Moderator
Tanya Telfair Sharpe, PhD, MS
Behavioral Scientist
Centers for Disease Control and Prevention

Speakers
Do Pediatric Residents Know the Five Areas of Development?
Mary Pavan, MD, FAAP
Assistant Professor, Department of Pediatrics at All Children's Hospital
University of South Florida College of Medicine

Pediatricians' Knowledge and Practice Behavior Regarding Fetal Alcohol Syndrome and Other Prenatal Exposure Disorders
Tanya Telfair Sharpe, PhD, MS
Behavioral Scientist
Centers for Disease Control and Prevention

A National Project to Educate Primary Care Providers About Down Syndrome: Defining Training/Information Needs, Preliminary Results
Diane McBrien, MD
Assistant Professor of Clinical Pediatrics, Co Director, Downs Syndrome Clinic at the Center for Disabilities and Development
University of Iowa, University of Iowa Hospitals and Clinics

Transcultural Training for Community-Based Perinatal Health Care Providers
Brenda Sumrall Smith, MSW, PhD
Board of Directors
National Perinatal Association

The Role of Bright Futures in Health Communications
Tom Tonniges, MD
Director, Department of Community Pediatrics
American Academy of Pediatrics

The complexities of current medical systems and community health programs require that physicians have comprehensive knowledge of integrated systems of care beyond the traditional medical models of disease and treatment. Beginning in infancy and throughout the life course, high quality health care is becoming increasingly based on integrated, multidisciplinary medical knowledge and is continually modified with advancing technology. This phenomenon is challenging to providers practicing in the field and challenging for medical and allied health schools. Medical provider education programs must navigate the amorphous landscape of current medical practices, shifting public health and social policy, and evolving science with an open ended perspective to meet the demands of training skilled health practitioners. In the session we examine four projects, each using different methodologies to ascertain provider knowledge, attitudes and practice behavior to inform medical education programs. First, we will review the results of an assessment of 64 pediatric resident's knowledge of the five domains of early childhood development outlined in the Individuals with Disabilities Act. Second, we will examine the results of a national pediatrician's survey regarding knowledge of the adverse effects of dose and timing of prenatal alcohol exposure. Third, we will review the results of a study to identify optimal provider health communication strategies for delivering information regarding the diagnosis and treatment of Down's Syndrome to parents. Fourth, we will experience insights garnered from education programs to enhance and improve perinatal health care professional's skills in treating patients of different cultural or ethnic backgrounds.

10:00 a.m. – 10:30 a.m. Break and Refreshments Regency Ballroom Foyer

Closing Plenary

10:30 a.m. – 12:00 p.m.

Personal Perspectives on Disability: Experiences Across the Lifespan

Regency Ballroom

Moderator
Margaret Giannini, MD
Director, Office of Disability
Department of Health and Human Services

Speakers
Living with a Disability: Challenges and Opportunities
Lex Frieden, MA
Senior Vice President
The Institute for Rehabilitation and Research

The Realities of the Autism Epidemic: A Parent and Advocates View
Rick Rollens
Co-Founder
MIND Institute

Disability has emerged as an important public health priority. With at least 50 million people living with a disability in the US, every individual, family, neighborhood, and community is affected. As advances in medical care improve the longevity of the general population and people with disabilities, it is likely that the proportion of the population living with a disability will continue to grow and benefit from public health initiatives. This plenary talk will address disability from a personal perspective and describe why improving the health of people with disabilities may require challenging traditional public health approaches to prevention.

Autism is no longer a single condition, but a spectrum of conditions that affect each person and family in different, but always significant ways. The Autism Spectrum Disorders (ASDs) are a growing health concern. The ASDs have enormous impact on the individuals, families and communities dealing with the many challenges associated with the ASDs on a day-to-day basis. These challenges include both advocacy and care-taking responsibilities. This plenary talk will discuss a family perspective on autism, illustrating the challenges facing families, and highlighting key areas where public health might better serve families and individuals with an ASD.

Post-Conference Events
Wednesday, July 28, 2004

Ancillary Meetings

1:00 p.m. – 4:00 p.m.	Center for the Evaluation of Risk to Human Reproduction (CERHR) Committee Meeting	Committee Room
1:00 p.m. – 5:00 p.m.	Early Hearing Detection and Intervention (EHDI) Federal Interagency Advisory Committee Meeting	Embassy Room
1:00 p.m. – 5:00 p.m.	Disability and Health State Grantees Meeting	Empire Room
1:00 p.m. – 6:00 p.m.	NBDPN Executive Meeting	Ambassador Ballroom
1:00 p.m. – 8:00 p.m.	National Council on Folic Acid Meeting	Diplomat Room
1:00 p.m. – 9:30 p.m.	Autism and Developmental Disabilities Monitoring (ADDM) Network and Centers for Autism and Developmental Disabilities Research Epidemiology (CADDRE) Surveillance Meeting	Executive Room

Post-Conference Events
Thursday, July 29, 2004

Ancillary Meetings

8:00 p.m. – 4:00 p.m.	Disability and Health State Grantees Meeting	Empire Room
8:00 a.m. – 5:00 p.m.	Autism and Developmental Disabilities Monitoring (ADDM) Network and Centers for Autism and Developmental Disabilities Research Epidemiology (CADDRE) Surveillance Meeting	Executive Room

Ancillary Meetings are generally by invitation only and are arranged by various individuals, groups, funded partners, or constituents.

ABSTRACTS

A Different View of Birth Defects as a Cause of Mortality: Using Birth Defects Registry Data to Evaluate the Full Effect of Birth Defects on Infant and Childhood Mortality, to Examine the Relative Risk of Mortality and Determine the Cause of Death Distribution among Children with Birth Defects

Author: *G. Copeland*

Background: The impact of birth defects on mortality is customarily evaluated using death certificate data and is normally limited to evaluations of the impact on infant deaths. Birth defects registries are ideally suited to monitoring mortality among birth cohorts and developing more meaningful data on the mortality experience of children with birth defects.

Method: A cohort of deaths to all children from among the 1.1 million live births born between 1992 and 2000 in Michigan to Michigan resident mothers was developed that included 12,672 such deaths occurring between 1992 and 2002. All deaths in the database were coded to ICD 9. Causes of death were grouped into the NCHS cause code groupings used for ranking. The database was linked to the Michigan live birth and Michigan Birth Defects Registry (MBDR) files. The study file included 4,354 cases of death to children in the registry and 8,318 comparison cases. Data for the MBDR cohort were compared to all other Michigan children relative to rate of death, cause of death and age at death. Additional mortality and cause of death comparisons were made for major birth defect diagnostic groupings

Result: Children with birth defects constitute as high as 40 percent (for age at death of 1 but less than 2 years) of all deaths in Michigan to infants and to children under 10. This compares to the routine observation from death statistics that 1 in 5 infant deaths are due to birth defects and highlights the lack of attention to the impact of birth defects on deaths in early childhood. The relative risk (RR) of mortality is 6.7 times higher in MBDR infants and 7.4 times higher in children 1 through 9. Relative risks of death due to endocrine disorders (RR 28.5 for < 1), CNS (RR 28.1 for <1, 24.5 for 1-9) and heart disease (RR 21.8 for <1, RR 21.8 for 1-9) are markedly higher. MBDR mortality is higher, however, in all cause categories. As an example, external causes of death are much more common in the cohort. Relative risks were determined for accidents (RR 1.9 for < 1, 1.4 for 1 - 9) and homicide (RR 1.8 for < 1, 3.9 for 1 - 9). A review of homicide deaths by diagnostic category finds the greatest risk among children with maternal exposures affecting the fetus, including FAS.

Conclusion: The relative impact of mortality among children with birth defects is significantly understated by traditional cause of death statistics. Cause of death information from death certificates does not adequately portray the full impact of birth defects on infant and childhood mortality.
- The use of birth defects registries to evaluate mortality can provide a precise and more meaningful picture of the full consequence of these conditions.
- The significance of birth defects on mortality in children under 10 is actually greater, in terms of relative risk and proportions of all such deaths, than for infant death.

Public Health Implication: Children with birth defects are at extremely high risk for mortality and offer an obvious target group for intervention strategies.
- Interventions that are comprehensive and address a range of needs beyond targeting the specific birth defect are indicated to reduce mortality due to other causes of death that constitute a higher risk for these children.
- Goals for reducing birth defects, improving the timing and completeness of referral to services and objectives for reducing mortality rates among children with birth defects need to be considered and shaped into specific objectives by maternal and child health intervention programs.

A National Project To Educate Primary Care Providers About Down Syndrome: Defining Training/Information Needs, Preliminary Results

Authors: *D. Helm, C. Kreutzer, D. McBrien, E. Hsu, M. Memmot*

Background: Despite significant advances in recent decades regarding medical and educational services for persons with Down Syndrome, anecdotal evidence from parents of children with Down Syndrome suggest that application of these advances by medical providers when counseling parents is less than satisfactory. Current literature indicates that dissemination of information alone is not adequate to affect utilization by physicians. The model proposed by this project relies heavily on user input, content experts, secondary research and the continuous refinement of conceptual models.Before developing content for training physicians, the project conducted a formative research

study to identify optimal information and preferred delivery methodology.

Method: Following IRB approval in each of the three participating hospitals, project partners in California, Massachusetts, Iowa conducted formative evaluation research in each state including key informant interviews, parent focus groups, and surveys with two groups: parents of children with Down Syndrome and physicians (pediatricians, obstetricians, family practice). The foundations of previous efforts were reviewed and evaluated prior to developing the evaluation research methodology and tools/questionnaires. Interviews and surveys assessed preferences in terms of content, product format and methods of delivery for training tools proposed for development.

Result: Key informant interviews were conducted with national professional and Down Syndrome organizations to identify existing resources and data on provider training needs. In each state, 8-10 parents of children with Down Syndrome participated in focus groups. Over 30 physicians participated in telephone interviews in the 3 states. They represented different types of providers and practice settings, in order to document geographical, structural and institutional influences on providers' knowledge, practice, perceptions, and training. Research data were then presented to content experts in Down Syndrome as well as representatives from national professional associations to guide the development of educational information for providers and parents.

Conclusion: Preliminary research data, methodology and tools used for conducting the formative research study will be presented

Public Health Implication: Primary care providers often do not lack access to educational information that could be shared with families after a diagnosis of Down Syndrome is made, instead, they lack time, training, experience and communication skills to deliver difficult news to families.Implementation of health communications marketing strategies to target a narrowly defined audience (physicians, parents) is needed to effectively meet training/information needs.

A Preliminary Study of DXA Positioning Protocols For Women and Girls with Mobility Disabilities

Authors: *M. Turk, J. Spadaro, J. Scandale, L. Logan, J. Calabrese, A. Shrivastava, and R. Weber*

Background: This study was conducted as part of a research program examining bone mineral density (BMD) in pre-menopausal women and girls with mobility impairments, in whom standard hip positioning required by the typical DXA protocol may not be achievable. Our objective was to establish a protocol compensating for contractures in DXA hip scans in people with mobility impairments using the DPX-IQ Lunar Pencil Beam Scanner.

Method: The participants were female volunteers without mobility impairments (n=14), aged 22-44, studied under IRB approval. Three sets of proximal femur scans were taken at 0º, 20º, and 30º of hip flexion, with repositioning between. The BMD in hip sub-regions and the precision of BMD with repeated scans at each angle were determined. Repeated DXA scans of the ipsilateral distal femur in lateral view were made for comparison to hip data as a potential surrogate site substituting for direct hip data. The main outcome measures were: a) Total and sub region BMD at 0º, 20º, and 30º of hip flexion. b) BMD in 4 sub-regions in the distal femur using generic lumbar spine scan protocol (g/cm2).

Result: Data analysis examined both the average standard deviation among repeats and the differences between 20º and 30º compared to the 0º positions. Statistical comparisons using paired t tests for the cohort indicated little change in hip BMD readings up to 20º flexion. At 30º hip flexion BMD appeared to increase in the shaft region and global reading by 9% and 7% respectively ($p<0.001$). There was modest correlation of the distal third lateral femur BMD with the hip shaft BMD ($r=0.55$) and neck BMD ($r=0.5$).

Conclusion: Hip flexion angles of >20ºcan give false positive or negative DXA readings. Distal femur readings correlate modestly with shaft and neck data, a possible surrogate site when typical extension is affected by contractures.

Public Health Implication: Women with physical disabilities who cannot attain the standard hip positioning required by the typical DXA protocols could still receive useable DXA information through the use of the alternate lateral femur site. The information could

be used to initiate treatments and possibly prevent avoidable injuries resulting from osteopenia or osteoporosis.

A Retrospective Process Evaluation of a Spanish-Lanugage Folic Acid Media Campaign: Tracking Trials and Tribulations

Authors: *E.Fassett, H. Carter, A. Flores, C. Prue, G. Miller, M. Volansky*

Background: Hispanic women have been shown to have an elevated risk of neural tube defects (NTDs) and lower levels of awareness and knowledge about the preventative benefits of folic acid. In 2001, an intensive Spanish-language campaign targeting Hispanic women was launched to increase levels of folic acid knowledge, awareness, and consumption using a combination of paid media and community outreach. An important part of campaigns is tracking implementation activities as they occur; this is often referred to as process evaluation. Due to CDC's involvement in national emergencies, the process evaluation was not done during the intervention periods. A retrospective process evaluation was completed to help characterize intervention activities so that findings from the outcome evaluation could be explained.

Method: English and Spanish-language information targeting Hispanic women of childbearing age was collected from a variety of media and non-media outlets in the two intervention markets and six comparison markets. Professional media monitoring services tracked the CDC-produced Spanish-language PSA, news stories related to folic acid, and print commercial advertising. Non-media efforts, including folic acid materials distribution and interpersonal communication efforts were collected through email and phone inquiries.

Result: In the 2001/2002 and 2002/2003 campaigns, intervention markets had more media "hits" than comparison markets (2001/2002: 1,400 vs. 51; 2002/2003: 995 vs. 44). However, comparison markets had significantly more non-media "hits" than intervention markets for both campaign periods (2001/2002: 44, 634 vs. 486,572; 2002/2003: 13, 391 vs. 61,980).

Conclusion: Due to the nature of retrospective tracking, researchers could only gain limited information about types of folic acid activities conducted during the campaign periods. Similarly, the ability to accurately track media activity was limited due primarily to the inability to obtain data retrospectively. Many campaign partners at the local level had difficulty in recalling activities during both intervention periods. The evaluation allowed researchers to gain a crude assessment of the campaign.

Public Health Implication: The process of retrospective data collection helped to clarify and create more rapid and real-time methods for tracking current and future campaign activities that have been successfully applied in the 2003/2004 campaign.

Active Living: How Community Features Can Promote Health For People Who Are Blind or Visually Impaired

Authors: *E. Gerber, C. Kirchner*

Background: Current public health literature is increasingly concerned over the rise in both obesity and inactivity among most sectors of the U.S. population, and the great number of secondary health conditions that will arise as a result. Data illustrate that this trend towards obesity and lower levels of physical activity is even greater among the blind population than the nation as a whole (NHIS 2001). While the field is concerned with the disproportionate disease burden shared by socioeconomically disadvantaged populations, the effect on people with disabilities generally, and those with visual impairments specifically, has been under examined. This paper addresses that gap, building on the "social model" of disability to measure the impact of the environment on the creation and experience of disability. This research examined aspects of the environment which can promote health (or, in their absence, act as barriers to well being) for people with visual disabilities.

Method: This exploratory research utilized primarily qualitative data collected during a period of one year from in-depth interviews, focus groups, and 200 surveys about criteria of "community livability" by people who are blind or visually impaired in the U.S. Data were transcribed and analyzed using The Ethnograph and SPSS. Further efforts are emphasizing objective measures to document the prevalence of "healthy features" in specific communities.

Result: Respondents indicated that the presence of health facilities, recreation centers, paths/parks, and general "walkability" are some environmental features that make communities livable. Moreover, they reported less obvious features that have health consequences,

such as good street lighting and low crime – since they would not walk if they did not feel safe – that have resonance with the larger population. Accessible public transit and the presence of unobstructed sidewalks are just several environmental features that act as "facilitators," enabling blind and visually impaired people to participate fully in their communities, including accessing medical care.

Conclusion: Environmental features can greatly influence the general health of the disabled population in the U.S., and in particular the access to physical activity available to the blind and visually impaired population under study.

Public Health Implication: There is much overlap between the needs of the blind population and others, notably the elderly (i.e., slower traffic signals, street lighting), persons with preexisting diseases or inadequate health care (i.e., facilities within walking distance), and increasingly, the general population suffering the health consequences of urban "sprawl."

Adolescent Knowledge and Health Practices In The Us Hemophilia Population: National Hemophilia Foundation Baseline Study and Adolescent Health Campaign

Authors: *A. Nazzaro, S. Crudder*

Background: The objectives of this presentation are: to provide information on knowledge and practice of preventive behaviors among adolescents with hemophilia and to discuss use of baseline survey data to inform the design of a health promotion campaign supporting the prevention of complications associated with hemophilia. Compliance with appropriate regimens and healthy lifestyles by adolescents has been problematic across several disorders. The National Hemophilia Foundation together with the CDC, designed this study as the basis for a national prevention campaign for hemophilic adolescents.

Method: A national, random and systematic sample of 459 respondents was drawn from patients at 20 randomly selected hemophilia treatment centers (HTCs) and eight hemophilia associations. Twenty-four percent of the sample consisted of youth with hemophilia ages 13-21. A 105-item telephone questionnaire measured demographics, attendance at and satisfaction with HTCs, information sources, knowledge, behaviors, and barriers to healthy practices. The purpose of the study was to then develop a national campaign to reduce or prevent the key complications of hemophilia, viz., joint disease and blood-borne viruses.

Result: Early treatment of bleeds and exercise ameliorate joint damage, yet 36% of the youth believed joint disease canNOT be prevented and 60% stated they manage hemophilia by avoiding physical activity. Only 31% stated that they treat a bleed within one hour of its occurrence in contrast to 52% of adults and 67% of parents of children with hemophilia. On social issues, 42% of adolescents stated that hemophilia causes problems at school or work.

Conclusion: For adolescents with hemophilia it was not only the stigma of treating a bleed in front of their peers that delayed treament, but it was also their difficulty in recognizing a bleed early enough. Results were used to develop and test prevention messages targeting adolescents—messages focusing on early treatment and the importance of physical activity to strengthen muscles and joints; and to determine key channels and venues for a national health promotion campaign.

Public Health Implication: With hereditary, chronic disorders, prevention as a concept needs to be taught and promoted strategically. Families and adolescents need help understanding that prevention of the secondary complications is within their control. Baseline KAB research and qualitative message testing remain sound building blocks of effective public health campaigns for a chronic disorder population as well as the general public.

Adverse Health Behaviors and Chronic Conditions In Adults with Disabilities

Author: *G. Jones*

Background: Adults with disabilities frequently have a slender margin of health that must be carefully guarded to prevent further disability. Recent research has shown that adults with disabilities often participate in adverse health behaviors at significantly higher rates than non-disabled adults. Research also indicates that physicians are less likely to initiate health behavior assessments of adults with disabilities. These practices may result in increased risk for potentially preventable chronic conditions that can substantially diminish their health and independence.

Method: We analyzed data from the combined 1997-99 National Health Interview Survey to assess the

effects of participation in health risk behaviors on the prevalence of five potentially preventable chronic conditions among adults age 18-64 years old, who said that they were current smokers, current drinkers, and physically inactive, and adults who met the Body Mass Index criterion for obesity (BMI<30).

Result: Adults with disabilities were significantly more likely to engage in adverse health behaviors and to have a higher risk for all chronic conditions studied than their non-disabled counterparts. Smokers with disabilities increased their risk for bone/joint problems, chronic pain, and depressive symptoms. Drinkers with disabilities evidenced a higher risk for chronic pain. Obese adults with disabilities (BMI > 30) had a higher risk for depressive symptoms, and physically inactive adults with disabilities raised their risk for bone/joint problems, chronic pain, depressive symptoms, and hypertension. These findings were even more striking by level of disability severity.

Conclusion: Adults with disabilities who smoke, overeat, use alcohol, or lack regular exercise may significantly increase their risk of having potentially preventable chronic conditions, such as depressive symptoms, chronic pain, bone and joint problems, and hypertension.

Public Health Implication: Adults with disabilities may experience improved health outcomes, greater independence, and enhanced quality of life, if health care providers (1) routinely assess their participation in adverse health behaviors as a part of their primary care, and (2) offer disability sensitive, accessible health promotion interventions to address potentially damaging risk behaviors. Health promotion for adults with disabilities should include both consumer and health care provider education on the detrimental effects of failing to assess and address health risk behaviors in adults with disabilities. The strong association between drinking status and chronic pain may indicate some use of alcohol among people with disabilities to self-medicate for persistent pain and should be investigated more thoroughly.

Approaches For Evaluation of Multiple Source, Population-Based Surveillance of the Autism Spectrum Disorders (ASDs) In The United States

Authors: *K. Van Naarden Braun, J. Baio, R. Kirby, M. Brimacombe, J. Nicolas, R. Kirby, M. Brimacombe J. Nicolas, C. Rice, N. Doernberg, J. Wojcik, M. Yeargin-Allsopp, D. Schendel, V. Harris, B. Becker-Cottrill, F. J. Meaney, C. Cunniff, S. Pettygrove, W. Zahorodny, F. Desposito, J. Charles, R. Brown, C. Newschaffer, R. Landa, J. Grether, L. Croen, L. Miller, C. Robinson, J. Pinto-Martin, E. Giarelli, S. Levy, J. Daniels, D. Savitz, M. Swanson, K. Scott, M. Yale Kaiser, J. Zimmerman, W. McMahon, J. Constantino, E. Trevathan, M. Durkin, M. Katcher*

Background: In recent years, there has been public concern about possible increases in the prevalence of Autism Spectrum Disorders (ASDs). To address this concern, the Centers for Disease Control and Prevention (CDC) recently established a collaborative, national network to monitor the prevalence of ASDs in children. The Autism and Developmental Disabilities Monitoring (ADDM) Network and the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) include 16 sites in 18 states. Differences in methodology between past studies have made direct comparison of past prevalence estimates difficult. An important aspect of identifying all children with an ASD is ensuring that identification of potential cases is as complete as possible.

Method: The evaluation of the ADDM/CADDRE Network surveillance system will use qualitative and quantitative approaches including: conducting stakeholders' working groups and surveys, use of the Network's data collection instrument to identify new providers, and capture- recapture and sensitivity analyses to evaluate the impact of missing cases on prevalence estimates. A three-tiered training and evaluation process should maximize quality and accuracy in data collection.

Result: Using prevalence and sample size estimates from prior CDC surveillance data, the planned evaluations assess the potential impact on the robustness of prevalence estimates across a range of reasonably expected outcomes. Preliminary findings from initial data quality evaluations will be presented.

Conclusion: The design of evaluation plans for population-based surveillance poses numerous challenges. However, thorough evaluation will help to ensure comparability of prevalence estimates across multi-site surveillance networks.

Public Health Implication: Evaluations of completeness of case ascertainment and data quality are necessary to ensure comparability of data generated by a common methodology and accuracy in prevalence

estimates. The evaluation strategies presented may be useful for other public health programs conducting multiple-source surveillance activities.

Assessing the Predictive Validity of a Kindergarten Screening Battery

Authors: *M. Scott, C. Delgado*

Background: The early identification of children with mild learning problems remains a challenge for educators. Children who are eventually given a classification of either educable mental handicap (EMH) or specific learning disability (SLD) are not typically identified until they have endured several years of failure and/or learning difficulties in grade school. The present research presents data regarding the predictive validity of a new kindergarten screening measure being evaluated as part of an overall program to develop screening instruments that will effectively identify preschool and kindergarten children at risk for mild leaning problems.

Method: A sample of 459 kindergarten children were administered a battery consisting of nine simple cognitive tasks in English, Spanish or both English and Spanish. Of this initial sample, 356 were located in the public school database when the children were in third grade. Of these, 345 were in regular education and 11 had either an EMH (n = 1) or SLD (n = 10) label. The racial/ethnic distribution of this sample was 41% Black, 35% Hispanic and 24% White. Fifty-six percent were male.

Result: : A subset of five measures enabled the correct identification of 91% of the special needs children (sensitivity) and 85% of the children who were in regular education (specificity). There was a high percentage of "false positives" but 57% of these children were poor achievers in third grade, earning percentile scores at, or below the 15th percentile on one or more of three achievement tests.

Conclusion: A brief cognitive screening set may well be effective in identifying kindergarten children at risk for special education placement or poor academic achievement.

Public Health Implication: Early identification may eliminate the subsequent negative association for school activities that typically develop in children who encounter failure and have other poor school experiences.

Assistive Technology and Adolescents with Spina Bifida

Authors: *K. Johnson, B. Dudgeon, C. Kuehn, T. Vollan*

Background: While individuals with spina bifida are likely candidates for the use of Assistive Technology (AT), little is known regarding the prevalence of AT use or complications with use in this population. Few in-depth evaluations of the benefits and rehabilitation outcomes have been completed. In addition, young adults with spina bifida are often transitioning towards adult responsibilities, such as post-secondary education, employment and independent living. AT often has a large role in this transition as individuals strive for greater access and acceptance in the community.

Method: Descriptive statistics were generated using a longitudinal database containing information on individuals with myelomeningocele, obtained from Children's Hospital and Regional Medical Center, in Seattle, Washington. The database contains records for 357 individuals (52% male & 48% female) who were between the ages 14 and 25 at their latest examination and included information on diagnostic and demographic characteristics, functional performance, and AT use.

Result: At time of latest assessment, 78% lived with one or both natural parents and siblings. 24% had completed high school and 6% had gone on to post-secondary education. The rest were either still in school or had dropped out before HS completion. 72% were not employed, with 13% having partial or gainful employment.

Analysis of disability and medical technology use finds that 72% had a shunt in place, 35% use a time bowel program and may use suppository or enema (20%) with digital stimulation (8%). For bladder management, 51% use clean intermittent catheterization, and 20% rely on some use of diapers or incontinent pants. Nearly half to the sample had scoliosis, most commonly of the thoracolumbar spine (31%).

Regarding assistive technologies for mobility, 57% make use of a manual or power wheelchair, with 35% using braces and 24% using some form of walking aide for ambulation. 39% report independent ambulation throughout the community, 29% report wheelchair independence in the community, and another 15% report independence with combined uses of braces and wheelchairs for outdoor and long distances. 37% drive an automobile or use public transit independently. We will describe in depth the sample and further identify key issues relative to performance and participation.

Conclusion: A significant number of adolescents and young adults with spina bifida rely on medical technologies and special care routines to maintain health. They are also using AT for mobility, but little is known about secondary complications such as musculoskeletal overuse syndromes and other challenges associated with wheelchair and walking-aid use. In addition, potential uses of AT to address learning disabilities and other barriers is not evident. These challenges may be delaying or restricting transitions toward independent living and full-participation in the community. We will describe ongoing research to clarify issues around the uses of AT as well as other barriers that may be enabling or limiting performance and participation.

Public Health Implication: This unique study looks intensively at the uses of AT among young adults with spina bifida. Information on AT use within this population is important in order to assist these individuals towards maintaining health, carrying out adult activities and enabling full community participation.

Association Between Maternity Care Coordination Services and Referral To The Child Service Coordination Program Among Infants with Down Syndrome

Authors: *C. Cassell, R. Meyer, F. Simsek, A. Farel*

Background: Timely identification and referral of infants with birth defects to specialized programs is critical to their overall health and development. Birth defects surveillance systems can help determine whether women and infants receive maternity care coordination (MCC) services, a Medicaid-eligible program, and whether such services influence referral to the Child Service Coordination Program (CSCP). The purpose of this study is to determine if the receipt of MCC services increases the likelihood of referral to the CSCP among infants with Down syndrome.

Method: Data from North Carolina Vital Statistics, the CSCP, and the NCBDMP were matched for 1999-2000. We determined the percentage of infants referred to the CSCP among women who did and did not receive MCC services. In addition, we determined percentages for the state's six perinatal regions of residence and for the following selected characteristics: marital status, number of living children, WIC status, Medicaid status, presence of other anomalies, hospital level of care at birth, source of prenatal care, and maternal age, education, race/ethnicity, and residence.

Result: From a total of 264 mothers of infants with Down syndrome, 14.4% received MCC services and 76.5% of infants were referred to the CSCP. Among women who received MCC services, 73.7% of infants were referred to the CSCP. Similarly, 76.7% of infants were referred to the CSCP among women who did not receive MCC services. Crude bivariate analysis indicated that among infants with Down syndrome, the odds of being referred to the CSCP among those who received MCC services was 0.84 (95% confidence interval: 0.38, 1.84) times the odds of being referred to the CSCP among those who did not receive MCC services. We found geographic differences in referrals to the CSCP, with the highest percentage found in the southeast (85.7%) and lowest percentage in the eastern (64.7%) perinatal region. We found statistically significant differences with the presence of other anomalies and source of prenatal care. We conducted both stratified and multivariate analyses to determine possible confounding factors.

Conclusion: Our analysis demonstrated that a majority of women did not receive MCC services and receipt of MCC services was not associated with referral to the CSCP among infants with Down syndrome.

Public Health Implication: This study has direct public health policy implications for how much Medicaid should be used to facilitate MCC services and the CSCP. It also suggests that population-based birth defects surveillance systems can play an important role in child-find efforts in identifying children in need of specialized health services.

Asthma, Asthma Medication Use And Risk of Cardiovascular Malformations In The National Birth Defects Prevention Study

Authors: *E. Bell, C. Druschel, M. Browne, A. Mitchell, A. Lin*

Background: Few studies have investigated the relationship of asthma and asthma medication use to the risk of congenital heart malformations. Previous studies were generally based on small numbers of cases and often grouped all congenital malformations together, limiting the ability to identify risks in etiologically similar groupings, such as cardiovascular malformations (CVMs). In a previous case-control study of CVMs in New York State, preliminary data suggested an increased risk for CVM among women who reported asthma and asthma medication use during pregnancy.

Method: Data on maternal illness and medication use, including timing of use, is collected as part of the National Birth Defects Prevention Study (NBDPS) interview. Using NBDPS data, we will compare maternal asthma and asthma medication use among CVM cases and controls. If numbers permit, we will examine specific classes of medications and subgroups of CVMs. Approximately 3300 cases and 2900 controls will be included in the analysis.

Conclusion: The large number of CVM cases and the available data on medication use will provide information on potential CVM risk associated with asthma and asthma medication use during pregnancy. Mechanistically similar subgroups of CVMs will be analyzed separately. Preliminary results of our analysis of the association between asthma, asthma medication use and risk of CVMs will be presented.

Public Health Implication: Since recent estimates indicate that asthma occurs in 4 to 8 percent of pregnancies and because drug treatment changes over time, it is important to develop better information on teratogenic risks associated with asthma and asthma medications. Given the increasing prevalence of asthma among women of childbearing age and the maternal health implications of untreated asthma, this analysis will contribute to current knowledge on the risks and benefits of asthma treatment during pregnancy.

Attitudes Toward Prenatal Testing Among Texas Women

Authors: *A. Peterson Case, T. Ramadhani, M. Canfield*

Background: Informed decision-making by expectant parents is essential for effective prenatal counseling about screening and diagnosis procedures. However, those providing the counseling may not be aware of the baseline knowledge (or lack thereof) and pre-existing attitudes held by their patients about the availability and utility of such testing. This study describes that baseline among the diverse population of women of childbearing age (WCBA) in Texas.

Method: The Texas Women's Health Survey is a 15-minute Computer-Assisted Telephone Interview of 1200 WCBA conducted in 1997 and 2001, focusing on women's understanding and behavior regarding various birth defect prevention topics. Black and Hispanic women were over-sampled to provide adequate representation. In this analysis, we examined responses to questions about "tests that can determine early in pregnancy whether a baby will have serious birth defects", as well as whether and for what reasons the respondents would assent to such testing.

Result: Preliminary analysis revealed that 86% of the women surveyed were aware of prenatal tests for birth defects, and 75% of those would choose to have testing. Stratifying by age, we found that women were more likely to be aware of these tests as age increased. However, women in their middle childbearing years (18-34) were more likely to say that they would choose such tests, compared to older women. Of those women that indicated that they would choose testing, most (98%) said that they would do so to prepare themselves and their families, while only 47% said it would be used to help decide whether to continue a pregnancy. Responses will also be presented by education level and race/ethnicity.

Conclusion: Responses varied considerably by age and other demographic characteristics. Although response to these questions indicated an overall acceptance of the utility of prenatal testing, in practice studies have found actual acceptance rates ranging from 50% (for genetic tests such as amniocentesis) to 70% (ultrasound).

Public Health Implication: Maternal health practitioners and policymakers should become familiar with their populations' existing knowledge and attitudes about prenatal testing so that they can provide appropriate patient education materials and counseling.

Audiologists and Early Hearing Detection and Intervention: Surveys from 3 States

Authors: *B. Shapiro, A. Jarrett, L. Pool*

Background: State agencies responsible for child health continue to adopt and maintain Early Hearing Detection and Intervention programs. These programs and the children they serve depend on networks of audiologists to evaluate babies after positive newborn screening, specify diagnoses, provide objective information to parents, provide and monitor aids. What are the policies and practices of these audiologists?

Method: Three states (Hawaii, Georgia and Michigan) independently surveyed pediatric audiologists licensed in those states. Efforts were made to maximize response rate. Survey results were summarized.

Result: Each state used slightly different questions and report somewhat different findings as to instrumentation used, state profiles of geographic availability of services, diagnostic criteria, ages served, services provided, etc. Findings from each state will be reported and similarities noted.
Each state is using the findings in different ways e.g. to create a directory of recommended audiologists or to advocate for more training, etc.

Conclusion: There is more variance within than between states as to instrumentation and types of services provided. Diagnostic criteria are not uniform. Some geographic regions have less access to audiology services. Other conclusions will be discussed with participants.

Public Health Implication: 1. Uniform guidelines for instrumentation and diagnostic criteria should be developed based on research or expert opinion.
2. States must devise creative ways to ensure prompt statewide access to competent audiological services.
3. States should develop methods to assess the reach, policies and practices of audiologists providing follow-up to newborn hearing screening.

Binge Drinking In The Preconception Period and Unintended Pregnancy

Authors: *L. Lipscomb, T. Naimi, R. Brewer, B. Colley Gilbert*

Background: Unintended pregnancy and binge drinking (having 5 or more alcoholic beverages on one occasion) are each associated with adverse health outcomes for women and children. This study examined the relationship between unintended pregnancy and binge drinking in the 3 months prior to pregnancy (the preconception period).

Method: The authors conducted a study of women with pregnancies resulting in a live birth. Data from 15 states participating in the Pregnancy Risk Assessment Monitoring System (PRAMS) from 1996-2000 were analyzed. Data were collected 2-6 months postpartum using a mailed questionnaire; nonrespondents were followed up by phone. Response rates exceeded 70%.

Result: Of 94,527 respondents, 14% reported preconception binge drinking and 43% reported an unintended pregnancy. Compared to women with intended pregnancy, women with unintended pregnancy were more likely to be young, black, less educated, and unmarried. In the preconception period, those with unintended pregnancies were more likely to receive Medicaid, smoke cigarettes, be exposed to physical violence, and report preconception binge drinking (16.2% vs. 11.8%; OR=1.45, 95% CI: 1.36, 1.54). After adjusting for potential confounders, preconception binge drinking was associated with unintended pregnancy for white women (AOR=1.63, 95% CI: 1.49, 1.79), but not for black women (AOR=0.99, 95% CI: 0.81, 1.22).

Conclusion: Binge drinking prior to pregnancy was associated with unintended pregnancies resulting in a live birth among white women, but not among black women.

Public Health Implication: Comprehensive interventions to reduce binge drinking may reduce unintended pregnancies, as well as other adverse maternal and pediatric outcomes associated with this behavior.

Biomarkers of Alcohol Abuse In Pregnant Women As Risk Indicators For The Development of FAS and FASD

Authors: *K. Strauss, J. O'Kane, J. Cook*

Background: Fetal alcohol syndrome (FAS) and fetal alcohol spectrum disorders (FASD) represent the largest categories of preventable mental retardation syndromes and birth defects. It is difficult for clinicians to identify those pregnant women who use alcohol and to predict infant outcome. A biomarker or panel of biomarkers to identify those women who drink and to predict the risk of FAS/FASD would be invaluable. The clinical utility of specific biomarkers in predicting maternal alcohol use and in assessing infant outcome was evaluated by comparing maternal alcohol use, infant birth indices and infant and maternal biomarker results.

Method: Study subjects included pregnant women, both drinkers and teetotalers, and their infants. The evaluated biomarkers included g-glutamyl transferase (gGT) by reflective spectroscopy, mean corpuscular volume (MCV) by focused flow impedance, carbohydrate-deficient transferrin (CDT) by capillary electrophoresis, and hemoglobin-associated acetaldehyde (HAA) by HPLC. Maternal self-report of alcohol use was determined by the AUDIT questionnaire administered at enrollment. Maternal biomarker analyses were performed at enrollment, at each of the three trimester ultrasound studies, and at delivery. Infant biomarker analyses were performed on cord blood.

Birth information including gestational age, length (BL), and head circumference (HC), was obtained on each infant.

Result: To date, preliminary data on 45 women, 17 teetotalers and 28 who ingested alcohol sometime during pregnancy, and 26 infants are available. The women were classified based on their AUDIT score using a cut-off of 4/40. For each variable only the mean and data range are presented because insufficient numbers have been enrolled to achieve a level of statistical significance.

Conclusion: Additional subjects and data are needed before the clinical utility of these biomarkers can be assessed.

Public Health Implication: Alcohol biomarkers that are predictive of maternal alcohol use and indicative of infant outcome are important in diminishing the rates of FAS and FASD. These markers would also be valuable in identifying those women needing intervention to decrease their alcohol use and in monitoring the efficacy of the intervention.

Birth Score System and Newborn Hearing Screening in West Virginia

Author: *M. Baker*

Background: All West Virginia birthing facilities are required, by legislation, to screen each infant born in their facility and assign each a score based upon risk assessment. The Birth Score System's goal is to reduce the incidence of preventable postneonatal mortality and disease by identifying, at birth, those infants most likely to have health problems during their first year of life. As a joint task, infant hearing screenings are collected on the same card and reported to the Newborn Hearing Screening Project. The Project and System work in collaboration with Children's Specialty Care, Children's Special Health Care Needs, and Birth To Three programs to identify infants at greatest risk for developmental delays due to hearing loss.

Method: The results of the infant's hearing screening done prior to discharge are reported to the Newborn Hearing Screening Project. Infants who fail the initial screening, are not screened, or have high birth scores are referred to community based providers of the state's perinatal program, Right From The Start (RFTS) services to assure diagnostic follow-up or case management. RFTS facilitates referral to support systems for the infant and family in the event of hearing loss or risk of developmental delays.

Result: Prior to legislative mandate, newborn hearing screening rates for WV infants were: FY1998 – 35%, CY1999 – adequate information not available, CY2000 – 65%, CY2001 – 96% and CY2002 – 97%. Since the July 2000, implementation of the Newborn Hearing Screening project, 60,258 infants have been screened either prior to hospital discharge or before 1 month of age. The current screening rate of infants, prior to discharge, is 97%. One hundred five (105) infants have been diagnosed with hearing loss before their first birthday and referred to early intervention and support services through Birth To Three and the Ski Hi Preschool program. [Overall Birth Score rates can be presented as well.]

Conclusion: With the implementation of the Newborn Hearing Screening Project, the number of infants in WV screened for hearing loss has increased and those identified have received early diagnosis, amplification and intervention.

Public Health Implication: : The Newborn Hearing Screening Project provides literature to parents, training to hospital staff and technical assistance to case managers to help decrease the number of infants with speech and language development delays due to hearing loss. Through early detection and intervention of hearing loss, the risk of developmental delay is decreased.

Building an Online Bridge to the World of EHDI: An Overview of the CDC-EHDI State Profile

Authors: *R. Patel, M. Gaffney, R. Ing*

Background: The State Profile includes information about all aspects of the EHDI process, such as program structure, screening and referral procedures, tracking and surveillance systems, and educational materials. It is an online repository of EHDI-related information that is available as part of the CDC EHDI website. Part of the objectives of this tool is to assist states in program planning and evaluation, and to inform parents, other government agencies, and providers about EHDI programs across the country.

Method: Currently, the State Profile is based on two types of surveys: the general CDC EHDI questionnaire

which can easily be updated on a regular basis, and annual data surveys. States can update their own information on the CDC questionnaire by securely logging in with their designated user name and password. The login credentials that allow users to edit information are confidential and maintained only by select CDC staff. To assure data quality, the CDC receives all updates made by states in a specific email account and approves the changes before they appear on the State Profile website.

Result: The State Profile would increase awareness among parents, providers, legislators, and the general public who wish to educate themselves about components of the EHDI process and the state of programs in U.S. Also, state public health officials who hope to learn about other programs will have the information readily available to them.

Conclusion: The CDC will be analyzing the State Profile data to draw conclusions about the regional difference in EHDI programs.

Public Health Implication: It is anticipated that the State Profile will serve as a comprehensive and up-to-date resource for state programs, parents, and other stakeholders to find a variety of program and process information related to EHDI.

Burden of Congenital Rubella Syndrome Following a Community Outbreak Of Rubella Among School-Age Children, Recife, Pernambuco, Brazil, 1999-2000

Authors: *T. Lanzieri, M. Parise, L. M. V. de O. Salerno, M. Siqueira, B. Fortaleza, T.C. V. Segatto, D. R. Prevots*

Background: During 1998-2000, a large rubella outbreak was reported from Recife, the capital municipality of Pernambuco State, in northeastern Brazil. In 2002, a study was conducted to assess the burden of congenital rubella syndrome (CRS) following this outbreak.

Method: We analyzed rubella case data available from the National Notifiable Disease System. Suspected rubella cases were confirmed by laboratory, epidemiological link or clinically. A retrospective record review for CRS was conducted at six maternity hospitals where 53% of Recife's resident live births occurred during 1999-2000, and one tertiary health care center. Suspected CRS cases were defined as infants with any manifestation of CRS or maternal infection during pregnancy. Compatible cases were defined based on standard international clinical case definitions, and those with anti-rubella IgM antibodies were classified as confirmed CRS cases. We estimated direct CRS costs based on reimbursements by the national health system.

Result: From October 1998 to July 2000, Recife reported 681 confirmed rubella cases: 40% by laboratory and 56% clinically. The highest incidence of rubella was among children 5 to 11 years of age (5.4/1,000 population). Forty-five suspected CRS cases were identified in this study. Clinicians suspected CRS in 16 (52%) of 31 compatible cases. However, only two had been screened for anti-rubella IgM despite free testing and only 1 had been reported. Cardiopathy, the most frequent clinical manifestation (94%), was associated with either cataracts, hearing impairment or both in 48%. The average annual incidence of CRS was 1.1 per 1,000 live births during 1999-2000. Costs for the first year follow-up, including surgical repair of congenital heart disease and cataracts, were estimated at an average of US$2,720 per child, for an overall cost of US$62,650 in this cohort to date.

Conclusion: Every effort should be made to attain high rubella vaccination coverage to prevent the severe congenital disabilities and high economic costs of CRS. Increased clinician awareness is critical for early CRS detection and prompt, complete reporting is essential to evaluate the impact of vaccination programs, and to document progress towards the regional goal of CRS elimination in the Americas by the year 2010.

Calculating the Indirect Costs Of Birth Defects, Developmental Disabilities, or Disabling Conditions: Productivity Estimates for the United States

Author: *S. Grosse*

Background: Calculation of the indirect costs of conditions requires estimates of the productivity lost as a result of premature mortality, morbidity, or disability. From the societal perspective, productivity is the total value of economic goods and services produced by a person unaffected by the condition. This includes gross earnings and the value of services produced in the household. The indirect cost of disabling conditions can be calculated by applying estimates of average productivity to information on reductions in paid work and personal care activities. The cost of premature mortality is the present value of future market work and household services.

Method: Earnings were calculated for each age and sex group using year 2000 labor survey data. Fringe benefits, including payroll taxes, were estimated on the basis of employer surveys and added to earnings to calculate gross compensation. Household services were calculated on the basis of time use data collected during 1992-94 in the National Human Activity Pattern Survey, valued by estimates of the replacement cost of hiring workers to produce the same services. Age-sex-specific estimates are presented of current productivity and discounted lifetime productivity, using a range of discount rates from 0% to 10%. Estimates are presented for earnings losses and for combined paid and unpaid work. Previously published productivity tables will be updated in 2003 dollars.

Result: The present value of future earnings and household production in 2000 was $1 million at birth, rises with age to peak at $1.4 million among adults ages 20 to 30, then decreases to $1 million at age 45, $0.4 million at age 60, and $115,000 at age 75, assuming a 3% discount rate. Tables of estimates are provided for discount rates ranging from zero to 10%.

Conclusion: The present value of future productivity rises with age until early adulthood, then decreases with advancing age but remains an important component of the economic impact of disability, even among older adults.

Public Health Implication: CDC has recently published estimates of the economic costs associated with mental retardation or intellectual disability, with costs of over $50 billion for each birth cohort. Over 80% of those costs are indirect costs. New estimates of the economic gains from folic acid fortification resulting from prevention of spina bifida and anencephaly also incorporate indirect cost estimates of foregone productivity. Understanding how economic productivity is defined and estimated is crucial for the interpretation of estimates of the economic costs associated with birth defects, developmental disabilities, and other disabling conditions and of the economic benefits of prevention programs.

Change In Alcohol Consumption Among Latinas of Reproductive Age

Authors: *C. Chambers, S. Hughes, M. Hovell, D. Wahlgren, S. Meltzer, and E. Riley*

Background: Effective methods to reduce alcohol exposure before conception are critical to preventing alcohol-affected children. We tested whether an intervention in non-pregnant, current-drinking low-income Latinas will influence intention to reduce or avoid alcohol in anticipation of a future pregnancy.

Method: Latinas were recruited from WIC sites in San Diego County, California, for in-home interviews followed by a randomized intervention involving a brief, tailored feedback message. Previously, we presented baseline data for 79 subjects showing that 60% reported >=4 drinks per occasion or >=7 drinks per week, and 27% reported inconsistent contraception. To date, 15 women in the intervention group and 19 in the non-intervention group have completed 3-month follow-up interviews. We compared the groups on change in alcohol intake, intention to modify alcohol intake in anticipation of a future pregnancy, and knowledge about the prenatal effects of alcohol.

Result: At baseline, none of the controls and 3 of the women in the intervention group were considered risky drinkers with respect to the potential for an exposed pregnancy (based on both alcohol consumption and birth control practices). At follow-up, 2 of the 3 risky drinkers (67%) in the intervention group reported a reduction to more moderate drinking while the other drinkers had not altered their behavior. If there was a chance that they might get pregnant, all 3 risky intervention drinkers (100%) said they would stop drinking until sure they were not pregnant, compared to 11/12 (92%) of moderate drinkers in the intervention group and 14/19 (74%) of the controls. Women in the intervention group were more knowledgeable than the controls about the Fetal Alcohol Syndrome.

Conclusion: These results, although based on preliminary data from an ongoing study, show promise with regard to behavior change, attitudes and knowledge among low-income Latinas who are likely to become pregnant.

Public Health Implication: Should this brief intervention strategy prove effective, the potential for prevention of early pregnancy exposure to alcohol could be substantial.

Community Organization To Reduce Disability

Authors: *S. Kinne, D. Lochner Doyle, A. Brothers, D. Patrick*

Background: Reducing the contribution of community environment to disability is important, but is difficult for several reasons. People with disabilities need different things from the environment in order to be able to participate fully in personal or community activities, so environmental changes may help only some individuals. Some disabling or enabling aspects of environment have been identified, but it is not clear how these affect health and participation. Finally, it is hard to know who is responsible for changes, since many agencies control different parts of the policy and social environment. This suggests that work to improve environments must be specific to each community.

Method: Community organization has provided a flexible structure for the process of identifying interested parties and common problems, prioritizing and choosing solutions, and working with local partners to reduce barriers affecting health and well-being in two Washington State communities.

Result: In each community, the tasks of identifying organizational homes for the project, responding to local needs, community assessment, gathering local disability data, program development, evaluation, and sustaining enthusiasm and participation taught lessons.

Conclusion: Reducing disability-related community barriers through community organization requires flexibility and patience, but is a necessary complement to health promotion interventions for individuals with disabilities.

Public Health Implication: Public health emphasizes the importance of community environment in promoting health and reducing chronic disease, and currently focuses on ways that communities' design promotes physical activity. Community organization to change disabling environments, driven by the social model of disability, is a way to bring disability prevention into mainstream public health.

Comparing States Using Survey Data On Health Care Services For Children With Special Health Care Needs

Authors: *M. Bramlett, S. Blumberg*

Background: This presentation offers a look at state-by-state differences for over a dozen key indicators of health, health insurance, access to care, and family impact for children with special health care needs (CSHCN). The National Survey of CSHCN was funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, and was conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention. In 2001, this random-digit-dial telephone survey identified and selected approximately 750 children with special health care needs from each state and the District of Columbia.

Method: Data from the National Survey of CSHCN were analyzed within each state and the District of Columbia for 15 key indicators, consisting of the proportion of CSHCN whose condition greatly or often affects their ability to do things other children do, with 11 or more days of school absences due to illness, without insurance at some time in past year, with any unmet need for specific health care services, with any unmet need for family support services, without a usual source of care, without a personal doctor or nurse, without family centered care, with out-of-pocket medical expenses exceeding $1,000, with family financial problems due to the condition, with families who spend 11 or more hours per week providing or coordinating care, and with family members whose employment has been affected by consequences of the condition. The values for each indicator were converted to standard scores, and a composite score for each state was developed by averaging the 15 standard scores. States were then ranked on this composite score.

Result: Rhode Island, Massachusetts, and Iowa were ranked lowest/best. Mississippi, Montana, and Florida were ranked highest/worst. The composite scores were related (r = .71) to state-by-state differences in the percent of children living below 200% of the Federal Poverty Level.

Conclusion: States differ, sometimes substantially, on the health care service needs of CSHCN within their state.

Competing Discourses of Mothering: Implications for Pregnancy and Alcohol Related Health Campaigns

Authors: *L. Baxter, R. Hirokawa, J. Lowe, P. Nathan, L. Pearce*

Background: The authors designed, implemented, and evaluated the effectiveness of a broad-based and localized media campaign about drinking and pregnancy directed toward low-income pregnant women and what we termed their "mentor Mom." Our approach is grounded in intermedia theory, which posits that

behavioral outcomes are not the direct effect of media messages alone but rather communication between the targets and the networks of others with whom they interact.

Method: The project consisted of four parts: Phase I comprised formative research to determine what our sample of 51 female WIC clients understood to be the effects of alcohol in the developing fetus, investigate our sample's attitudes, beliefs, and practices regarding the use of alcohol during pregnancy, and examine their intermedia communication practices relevant to the topic of alcohol and pregnancy. In Phase II storyboards based on the findings of our Phase I research were developed and pilot tested. Phase III involved the production of 3 mediated messages: a broad-based 30-second TV commercial; a 10-minute video, and a printed pamphlet. Phase IV evaluated, through a randomized control design, the effectiveness of the mediated messages in pretest-posttest surveys of 700 WIC clients drawn from all 99 counties of Iowa.

Result: The formative research identified two competing discourses of motherhood, the discourse of individualism and the discourse of selfless mothering, that complicate the reception of intermediated communication about drinking during pregnancy. This knowledge informed the approach and content of the mediated messages.

Conclusion: Both discourses affect the way women receive, process and re-transmit information about alcohol and pregnancy.

Public Health Implication: This session introduces intermedia theory as a new and potentially highly effective approach to health promotion.

Congenital Heart Defects In Utah: Type of Pregnancy Outcome and Timing of Diagnosis Impact Completeness and Reporting

Authors: *M. Feldkamp, L. Young, L. MacLeod, J. Carey*

Background: Congenital heart defects (CHD) are the most prevalent of birth defects in Utah, occurring in one of every 180 births (excluding ventricular septal defects). The purpose of this study was to investigate the completeness of reporting sources for (CHD) cases identified to the Utah Birth Defect Network (UBDN). Reporting sources will be assessed to determine whether time of diagnoses, type of CHD, and pregnancy outcome impact frequency and prevalence.

Method: Data are derived from the CHD cases occurring between 1999-2002 in the UBDN. The UBDN utilizes multiple reporting sources to capture all potential cases of CHDs from all pregnancy outcomes (live births, stillbirths, and pregnancy terminations).

Result: A total of 1,854 CHDs were reported to the UBDN during the study period. Of these reported cases, 1,083 (58%) were classified as cases while 765 (42%) did not meet case criteria. CHD prevalence was 5.7 per 1,000 births with only 20% prenatally diagnosed. Stillborn and terminated CHD cases were more often pre- than postnatally diagnosed (stillbirth, 60.9% vs. 39.1%; TAB, 72.5% vs. 27.5%), whereas live births were less frequently identified pre- than postnatally (17.0% vs. 83.0%). For all CHDs, 22.3% were reported by only one of the many sources; 27.4%, by two; and 18.9%, by three. Overall, 74% of cases were identified from the pediatric cardiology clinic, followed by birth certificate (52%), newborn intensive care nursery (48%), and pediatric hospital discharge data (45%).

Conclusion: Multiple reporting sources are required to capture all CHDs. Informative reporting sources will vary based on the pregnancy outcome and time of diagnosis. Frequency and prevalence overall and for specific CHDs will vary based on timing of diagnosis and pregnancy outcome.

Public Health Implication: Critical to any surveillance system is the ability to identify as close to 100% of cases to report appropriate prevalence and determine if public health measures impact the baseline prevalence. Depending on the process of identification, evaluation, and classification, CHDs can be either over or under identified within a surveillance system.

Connecting Birth Defect Surveillance with Available Services In Minnesota

Authors: *B. Frohnert, , M. Falken, M. Alms, S. Thorson, J. Hurley, and D. Symonik*

Background: Minnesota is currently piloting the passive surveillance portion of a statewide Birth Defects Information System (BDIS). In addition to validating birth defects, the system is intended to connect eligible children and families with the state's Title V CSHCN program, Minnesota Children with Special Health Needs (MCSHN), to ensure they receive coordinated health

prevention and intervention services such as Part C of IDEA. Without a state birth defects surveillance system, children with birth defects may not be connected with available services in a timely manner.

Method: BDIS receives weekly reports of children with birth defects identified on their standard electronic birth certificate. Staff then go to birth hospitals to validate cleft lip/palate, neural tube defects, and chromosomal defects using medical records. BDIS informs MCSHN of the children with these validated birth defects. MCSHN checks if the child has already been connected to eligible programs. If not, MCSHN staff contact the family to connect them with available services.

Result: As shown by both national literature and Minnesota data, even the most apparent birth defects are not accurately identified on birth certificates. A large portion of the eligible children identified by BDIS had not been referred to the MCSHN program yet. Preliminary data show 7 out of 10 families did not know about all the materials and services available to them. Systematic communication between BDIS and MCSHN increased the number of families referred to resources within the state.

Conclusion: Additional development of both the active and passive birth defects surveillance in Minnesota must include efficient communication links between BDIS and MCSHN to assure all children are connected with appropriate services.

Public Health Implication: To assist families with meeting the special needs of their children, prevent children with birth defects from developing secondary conditions, and prevent the recurrence of birth defects in these families; families with children with birth defects must be linked promptly with programs like Title V and Part C of IDEA that educate parents and facilitate optimal child development.

Designing Community-Based Strategies To Improve Primary Prevention For People With Physical Disabilities In Virginia: Focus Group Findings

Authors: *T. Kroll, M. Neri, G. Jones, M. Goldstein, S. Michael*

Background: People with physical disabilities are less likely to receive primary preventive care services than the general population while they may be exposed to greater risks for an earlier onset of secondary conditions such as cardiovascular disease and loss of bone mineral density. This study seeks to determine barriers for access to and use of these services in the diverse community of Northern Virginia and to develop strategies and resource materials to improve primary prevention for people with physical disabilities.

Method: We conducted five focus groups with 40 adults who had various physically disabling conditions who resided in Northern Virginia. Further, we collected Internet-based poll data to ask respondents about their experiences with primary preventive service access and utilization. Individuals with physical disabilities were involved in developing and implementing of the focus groups and internet polls. They also made recommendations regarding the content and format of Primary Preventive Resource Kits for consumers with disabilities and their health care providers that will be developed later in the study.

Result: Respondents identified several barriers impeding access to primary preventive services. These included among others the lack of accessible information about preventive services, inappropriate and inaccessible screening equipment, the lack of communication about prevention issues on the part of physicians, and lack of physician time for counseling about health risk behaviors. Respondents also made recommendations to improve access to these services. They suggested creative avenues for information dissemination, preparing physician appointments, and recommendations for improved equipment and facility accessibility.

Conclusion: Adults with disabilities face a myriad of barriers that prevent them from obtaining needed primary preventive services. The community-based development of primary preventive resource kits may help facilitate access and use of these services among people with physical disabilities. The Northern Virginia program will produce a template for such resource information, which can be implemented with modifications elsewhere.

Public Health Implication: The development of community-specific educational strategies allows for greater customization and tailoring to the needs of a particular community, and as such has the potential to maintain the health of people with disabilities and avoid the shortcomings of more generic approaches.

Developing Child Health Information Systems to Meet Medical Care and Public Health Needs

Authors: *A. Hinman, K. Saarlas, E. Wild, N. Fehrenbach, D. Ross*

Background: Many single-purpose ("silo") information systems have been developed to serve individual program needs in areas such as newborn screening, immunization, birth defects surveillance, etc. These systems typically do not share information. Consequently, a provider (or other authorized user) has to separately query each of the systems to get a complete picture of the health status of an individual. There is increasing interest in integrating information systems to provide a range of information to the end user in a simple yet comprehensive format so he/she can readily take all appropriate actions. Provision of complete, timely, and accurate information can lead to improved health and health services for children.

Method: With support from the Robert Wood Johnson Foundation, we hosted a meeting in December 2003 on Developing Child Health Information Systems to Meet Medical Care and Public Health needs. Recommendations from the meeting are being used as a basis for further action. An important building block for progress in integrating child health information systems (CHIS) has been enunciation of principles and functions of integrated Child Health Information Systems (CHIS) supporting four programmatic areas – newborn dried blood spot screening, early hearing detection and intervention, immunization, and vital registration. With support from the Genetics Services Branch, Health Resources and Services Administration, we convened a core workgroup in May 2003 to develop principles and core functions. The product was subsequently circulated to an external review committee and presented in several forums for discussion.

Result: The December meeting developed a series of recommendations for action in the areas of governance, economic issues, information infrastructure, and use of information. The May meeting resulted in enunciation of 19 principles, 22 core functions, and 8 desirable functions for integrated CHIS. Results will be presented in detail.

Conclusion: The outlines of an action plan for development of integrated CHIS have been developed and further work is underway to refine the plan and implement it. Through a collaborative process it has been possible to define the principles and functions required of integrated CHIS. These will serve as important building blocks.

Public Health Implication: Integrating child health information systems will improve health and health care of children.

Developing Health Education Materials for Populations with Low Literacy Skills: Lessons Learned from "Emma's Story," an Easy to Read Story about Folic Acid and Preventing Birth Defects

Authors: *K. Kilker, P. Mersereau, A. Flores, C. Prue, E. Fassett, and H. Carter*

Background: According to the 1992 National Adult Literacy Study, the average American adult reads at a 7th grade reading level. A quick review of birth defect prevention education materials currently offered by CDC and other organizations provides a spread of materials written at grade level 12 and up. These factors, in addition to awareness rendered by the health literacy objective of Healthy People 2010, brought to light a gap in birth defect prevention efforts by way of written materials. To remedy this, our team set a goal of developing a birth defects prevention educational material designed specifically for adult new readers and others with limited literacy skills.

Method: To achieve this goal, we used knowledge gained from communications research, professional experience with the general public, and training opportunities to lay a "low-literacy" framework for the folic acid message. Our approach aimed to encourage women with low literacy skills who are contemplating pregnancy to take folic acid daily to prevent neural tube defects. We tested this health message in booklet format with the target audience at a variety of locations in the Atlanta area. Feedback was incorporated as the material was revised.

Result: The constant reshaping of the folic acid booklet resulted in a colorful, photo-filled, easy to read, and captivating educational material evaluated at a 6th grade reading level. Both the English and Spanish versions of our final booklet tested quite well with our target audience in terms of interest, comprehension, and message resonance. After 13 months in development, the booklet was released for distribution to the public in November, 2003. To date, three months after its release, we have had requests for almost 200,000 copies of the English and Spanish versions of

this material from across the country. Evaluation is ongoing, but preliminary feedback suggests that this booklet is an effective folic acid education tool for reaching a segment of the population that might otherwise "fall through the cracks."

Conclusion: This folic acid educational material is unique in that it aims to reach an at-risk population, who may not have been touched by the current array of educational materials, with an important birth defects prevention message. The testing and development of this material is one step toward establishing sensitivity to literacy in health communication endeavors as outlined by the health literacy objective of Healthy People 2010.

Public Health Implication: We hope to educate our colleagues about the importance of being sensitive to literacy limitations and to share the valuable lessons we learned in our experiences developing and testing this new material.

Development of a New Method For Assessment of Reproductive Toxicity By Epigenetic Analysis

Authors: *H. Fukata, K. Sato, M. Omori, M. Komiyama, K. Aida, E. Todaka, and C. Mori*

Background: Many of the endocrine disruptors have no or weak mutagenicity. However, it has been reported that some of them have long-term and/or late effects by transient exposure at fetal or newborn period. Therefore, we are investigating the relevance of epigenetic alteration on the mechanism of long-term effects and/or late effects by diethylstilbestrol (DES).

Method: Newborn C57BL mice were injected DES (0, 0.003, 0.3, 3 ƒÝg/mouse/day) subcutaneously at PND 1-5 and epididymides and uteri were collected at PDN30. Genome wide screening of DNA methylation status was performed by restriction landmark genome scanning (RLGS) using Not I.

Result: There were 4 Not I-sites differences (0.4 %) on DNA methylation between epididymides and uteri at PND30, while 22 sites of methylation status on uterus genome were changed by DES at some doses. The methylation status was altered depending on the dose of DES, that is, 8 sites were demethylated at higher dose and 7 sites were methylated at lower dose. When the number of sites of which the methylation status changed was counted, the number was increased according to the dose increase. Surprisingly, 20 out of 22 sites were different in methylation status between 0.3 ƒÝg and 3 ƒÝg of DES. On the other hand, at least 8 sites (0.9 %) of methylation status change were observed in epididymis. Next, we performed cloning and sequencing of 3 uterus-sites and 4 epididymis-sites. 3 uterus-sites did not exist in a CpG island, while 4 epididymis-sites existed in a CpG island of a promoter region.

Conclusion: It became clear that DNA methylation status was drastically changed by the transient neonatal exposure to DES. Sites in which the methylation status changed were not always present in the CpG island, in some cases it was changed at a Not I site in a downstream of a gene. Genes cloned from epididymides were characterized as a protein kinase, a zinc finger protein and an apoptosis-inducing protein and it was suggested that these genes were important for the epididymal function and involved in maturation of sperm in epididymis.

Public Health Implication: In the traditional risk assessment of chemicals, mutagenicity has been emphasized, but it was suggested from our study that endocrine disruptors had long-term and/or late effects caused by the epigenetic modification. In the future, it is necessary to assess chemical risk focusing on epigenetic mutagenicity which is inducible at low concentration level but multiple chemicals.

Development of Accessibility Instruments Measuring Fitness and Recreation Environments (AIMFREE) for People with Disabilities

Authors: *J. Rimmer, A. Rauworth, B. Riley, E. Wang*

Background: While engaging in regular physical activity is critical for maintaining good health and preventing secondary conditions associated with a sedentary lifestyle, persons with disabilities encounter major environmental barriers that often prevent them from fully participating in fitness and recreation activities. The purpose of this study was to develop valid and reliable measures of fitness and recreation facility accessibility which will serve as a tool for improving the accessibility of these facilities, as well as to raise public awareness regarding the need for greater access to fitness and recreation facilities for persons with disabilities.

Method: The study involved four phases of research: Phase 1. A national survey on the usage, interest and perceived accessibility of various fitness and recreation facilities was completed by 361individuals with disabilities to determine the most relevant fitness and recreation venues for this population. Phase 2. Focus groups were conducted with consumers with disabilities, architects, fitness professionals, and park district managers in nine regions across the United States to identify accessiblity barriers and facilitators to be included in the item bank of the instruments. Phase 3. Pilot testing involving both people with disabilities and fitness professionals was conducted in Chicago to finalize the development of the instruments. Phase 4. A national field validation trial was conducted with 40 fitness/recreation professionals and 54 consumers with disabilities in 76 facilities (36 fitness centers and 40 parks and trails) to assess the reliability and validity of the instruments.

Result: The types of facilities with the highest combined interest/usage ratings included community parks with walking paths and trails and gym/fitness centers with swimming pools. The final instruments contained 457 items measuring accessibility of fitness environments and 218 items for parks and trails. Field test data indicated overall good validity and reliability for the AIMFREE instruments. The results found that the 15 AIMFREE subscales evidenced good fit to the Rasch model (M Item Infit=0.99, M Item Outfit=1.07). Eight of the 15 subscales also evidenced adequate to good facility separation (¡Ý .70). In general, the test-retest reliability of the AIMFREE subscales ranged from .72 to .97

Conclusion: While the general fitness and recreation environment including parking, elevators, water fountains, and bathrooms was considered accessible, staff attitudes and behavior, inadequate signage, and access to hot tubs, saunas, swimming pools, trails, and picnic areas remain major environmental barriers for people with disabilities.

Public Health Implication: Simple accommodations and staff training in fitness and recreational facilities would make these environments more disability friendly and likely increase participation of people with disabilities.

Development of Assay for Adult and Adolescent Biomarkers of CRS

Authors: *K. Rhrissorrakrai, J. Icenogle*

Background: Congenital Rubella Syndrome (CRS) is the most vaccine preventable birth defect in the world. CRS patients suffer from a host of defects including seizures, heart abnormalities, deafness, endocrine dysfunctions and visual detrioration. It's known that immunological abonormalities exist from birth and altered humoral responses are seen in infants. These responses may serve as markers for detection of CRS in those who are undiagnosed at birth or to reclassify cases of CRS. Finding such markers would also be beneficial in the development of assays to determine the burden of disease due to CRS within a country, specifically those without a rubella program. Also, the detection of virus persistence in adults may shed light on to the pathogenesis of late-onset manifestations of CRS.

Method: 1) Quantitative Fluorescent Western Blot: Using fluorescent antibodies against human IgG antibodies in a rubella virus western blot, we were able to accurately measure the fluorescent signal and determine the percentage of antibodies to each of the viral glycoproteins E1 and E2, as well as the level of antibodies to the capsid protein (C). CRS patients are expected to have enhanced E2 response relative to postnatal infections. 2) Avidity (functional IgG affinity): Avidity was measured by comapring the reaction of diluted sera with rubella virus antigen with or without DEA, a mild denaturant, using ELISA detection. CRS sera should have lower avidity due to an abnormally slow response to virus, possibly even tolerance to the virus. Postnatal infection samples are expected to have higher avidity. 3) DI RNA: Long-term viral presistance is expected to yield defective-interfering RNAs as a consequence of continued viral replication. Thus it is reasonable that CRS survivors would have DI RNA.

Result: High E2 response was seen in all CRS sera, but in only 6/27 postnatal sera. C antibody signal was detected in 6/7 CRS samples but only in 14/28 postnatal samples. Low avidity was seen in all CRS samples and in only two postnatal samples. Testing for the presence of DI RNA has been inconclusive thus far.

Conclusion: Perhaps a combination of criteria, such as enhanced E2 response and low avidity, would be useful in establshing criteria for biomarkers of CRS.

Public Health Implication: Development of biomarkers would be useful in determing burden of disease, reclassifying patients, studying the pathogensis of CRS and in finding a real potential for elimination.

Development of Indiana Birth Defects Surveillance System Educational Program For Hospital Staff at Birthing Hospitals in Indiana

Authors: *K. Barton, D. Abatemarco*

Background: Children with birth defects and/or genetic disorders account for 40-50% of admissions to hospitals in Indiana. In spring of 2001, Indiana developed the Indiana Birth Defects Surveillance System (IBDSS). The main goal of an expanded surveillance system is to improve access to health services, early intervention, and prevention programs. In August 2002, a new law mandated all birthing hospitals in Indiana report birth defects to the Indiana State Department of Health (ISDH). By August 2003, 66 out of 108 hospitals submitted birth defects data accurately, 12 submitted data but with an incorrect format, and 31 had not yet reported. To improve reporting a plan was developed to train hospital staff on data submission and provide feedback to hospitals about the quality of their reporting.

Method: The training is comprised of 4 components: needs assessment, program development, implementation, and program evaluation. It is designed to train medical records directors and staff about the importance of reporting birth defects for the children's health needs and to teach the most efficient methods to reporting. Topics include: obtaining quality data, methods for sending data, state law and reportable conditions, technical issues, and common reporting errors. Participants completed pre- and post-test surveys as part of the process and impact evaluation of the program. Data was analyzed using Statistical Program for Social Sciences (SPSS).

Result: Approximately half (51%) of 108 birthing hospitals attended this pilot training program. 86 individuals attended the training. However, 67 participants (78%) completed the pre- and post-test surveys. There was an 18.8% increase from pre-to post-test. 83% reported that the training program met most or all of their expectations.

Conclusion: There has been an increase in hospital reporting to IBDSS since the training. Communication between ISDH and hospitals has improved. Internal ISDH tracking systems are continuously being improved. The IBDSS staff has doubled since July and a new program director was named. Efforts have increased in data collection, communication with hospitals, and training. Additionally, the budget is undergoing review for efficiency.

Public Health Implication: Based on the needs assessment and the evaluation the findings show that education and training are key to better birth defects reporting. Future plans should include physician training, continued improvement efforts to enhance the quality of data, followed by proactive communication to prevent problems.

Development of the Electronic Tennessee Child Health Profile

Authors: *K. Barton, D. Abatemarco*

Background: Integrated health databases have been advocated to improve health care delivery, to reduce redundancy/medical errors, and to eliminate endless paper trails from the point of health care services. Currently, several states are attempting to implement electronic child health profiles, building upon newborn metabolic screening programs mandated in most states. We present initial findings from the development and pilot phases of the electronic Tennessee Child Health Profile.

Method: The project utilizes the following databases gathered from the Tennessee Department of Health: Newborn Metabolic Screening (NBS) and Newborn Hearing Screening (NHS) (a Neometrics-developed database), electronic and manual birth certificate records, immunization registry data, and PTBMIS. Plans are to continue integrating further data in the future. NBS and NHS records are updated daily and imported via a secure VPN from the metabolic testing center to the integrated data warehouse, where the data is linked with other databases using common identifiers. The data warehouse, which is the core of the Tennessee Child Health Profile, is securely accessible by health care providers who have received parental/guardian permission to access the child's records. The database is evaluated for data accuracy, identifier linkages, and functionality prior to pilot testing.

Result: The data warehouse integrated the databases described. Accuracy of linked client records improved with generation of client identifiers, specifically the child's first and last names, mother's first, last and/or maiden names, child's birthdate, NBS unique identifier, and social security numbers.

Conclusion: The Tennessee Child Health Profile links several databases for efficient records access. The database addresses accuracy of linkages based upon common identifiers. The pilot test, involving case

managers and providers of NBS follow-up and treatment services, will lead to statewide implementation of the integrated data warehouse.

Public Health Implication: Integrated public health data improves health care service delivery, especially for children with special health care needs (e.g., inherited metabolic conditions).

Development of the Tennessee Genetics and Newborn Screening Website

Authors: *T. Blake, B. Wilson, D. Hollar, C. Lozzio*

Background: The World Wide Web has an increasing wealth of health related information that is easily accessible to consumer and healthcare providers (HPC). In addition to the expansion of newborn screening, two central goals of the Tennessee Genetics Plan are to increase consumer and HPC understanding of genetic conditions and empower consumers to be effective advocates for their child with special health care needs. We present the development of the Tennessee Genetics and Newborn Screening (TN GNBS) website and initial consumer feedback on this website.

Method: A total of 40 state genetics websites were evaluated for the 50 states and Washington D.C from September 2003 to October 2003. The remainder were inaccessible, under construction, or consolidated into one regional website (e.g., New England Newborn Screening Program). Qualitative evaluation of the 40 websites was divided between two evaluators and focused on the quality and quantity of content, ease of access, and additional resource links. With the information gathered, the TN GNBS website was developed. The website content was reviewed and editorial changes submitted by the Consumer Involvement Subcommittee and the Professional Education Subcommittee of the Tennessee Statewide Genetics Coordinating Committee (SGCC).

Result: Only 9 of the 40 (22.5%) websites provided ample, quality information with ease of navigation. Five of the 40 (12.5%) websites provided additional resource links for consumers and/or HCP. With this information, the TN GNBS website was developed with general information on the program, state clinical genetics services, a consumer/parent oriented section, a HCP oriented section, and information on the SGCC. In addition, general local and national resources were provided along with condition specific resources. Consumer feedback was mainly positive with only minor editorial changes integrated into the website. In addition, a section for consumer feedback will be available on the website.

Conclusion: The TN GNBS website integrates and expands upon the strengths of other state genetics websites. Preliminary feedback from consumers indicate the website is a high-quality source of information and resources. Additional feedback will be obtained from consumers through the TN GNBS website and incorporated with future revisions and expansion of the TN GNBS website.

Public Health Implication: The TN GNBS website provides consumers and HCP the opportunity to increase their understanding of genetic conditions (e.g., disorders associated with newborn screening) to ultimately improve and enhance the lives of children with these conditions.

Development of Toxicogenomic Newborn Screening with DNA Microarray Using Human Umbilical Cords

Authors: *C. Mori, M. Komiyama, H. Fukata, M. Omori, K. Aida, E. Todaka, and H. Osada*

Background: Our previous studies analyzing umbilical cords show that human fetuses are exposed to multiple chemicals in Japan. Human fetuses are thought to be significantly more sensitive to a variety of environmental toxicants (ETs) than adults. Therefore, it is urgently necessary to develop a new method of evaluating health risk factors to human fetuses of the possible long-term effects caused by prenatal exposure to multiple ETs. Recently, we introduced our attempts to apply toxicogenomic analysis of umbilical cords using DNA microarray to the future health risk assessment. Since the umbilical cord is a part of the fetal tissue, it is possible to estimate the effects of ETs on the fetus by the analyzing alteration of the gene expression. In this presentation, we will explain the usefulness of toxicogenomic analysis of umbilical cords using DNA microarray for future newborn screening. The key issue of newborn screening using umbilical cords is to find the potential high-risk group in the newborn. Both the actual high exposure and the genetic high susceptibility to multiple chemicals should be regarded as higher health risks to the individual.

Method: Human umbilical cords were collected from normal newborns at Chiba Univ Hospital. Informed

consent was obtained from all the mothers. In each umbilical cord, the chemical concentrations were measured by gas chromatography/mass spectrometry, and the gene expression was examined by DNA microarrays (Agilent Human 1 cDNA microarray or Affymetrix U133Plus2.0 human DNA microarray). We have analyzed the relationship between the concentration level of persistent chemicals (polychlorinated biphenyls [PCBs] and organochlorine pesticides) and the gene expression patterns in umbilical cords of 19 Japanese newborns. Gene expression profiles of the umbilical cords were analyzed by hierarchical cluster analysis and principal components analysis, then they were compared with the sum of chemical concentration profiles.

Result: 1) Chemical concentration analysis: The fetuses who accumulated PCBs at higher level had a tendency to accumulate other chemicals also at higher level. This result suggests that there are fetuses highly exposed to multiple persistent chemicals in Japan. 2) DNA maicroarray analysis: the sex of fetuses was clearly detected from examined umbilical cords. This indicates that global analysis of gene expression can detect the profile of gene expression altered by chemical exposure in umbilical cords. Indeed, the expression profiles mostly matched with the sum of persistent chemical concentration profiles in the umbilical cords. However, there was an exceptional case in which total concentration of the chemicals was lowest, but its gene expression profile was quite similar to those of the umbilical cords with higher total chemical concentration levels. These results suggest that the gene expression profile of umbilical cords can detect a potential high risk group from the actual high exposure and the genetic high susceptibility to multiple chemicals during fetal period.

Conclusion: Toxicogenomic analysis of human umbilical cords could be used as an effective newborn screening to detect potential high-risk group from the view of exposure level and susceptibility.

Public Health Implication: The main goal of our toxicogenomic newborn screening using umbilical cords is to find the potential high-risk group in the next generation, in order to prevent the long-term effects caused by fetal exposure to multiple chemicals.

Developmental/Neurological Profile of Infants In De Aar, Northern Cape, South Africa With Special Emphasis On Those With Fetal Alcohol Syndrome

Authors: *L. Fourie, J. Rosenthal, M. Nero, C. Molteno, D. Viljoen*

Background: Alcohol exposure during pregnancy affects the cognitive functioning of the unborn infant. It is the single most common birth defect & preventable cause of mental retardation worldwide. Studies in the Western Cape Province, Gauteng and De Aar regions of the Northern Cape Province have shown Fetal Alcohol Syndrome (FAS) prevalence amongst school-entry children to be 20-100 times more frequent than other common birth defects such as Down syndrome or Neural Tube Defects. A 3- year FAS prevention project implemented in De Aar in 2003 clinically demonstrated that 21 (7%) had FAS (n=302)). The Developmental assessment was undertaken together with the clinical examination & maternal questionnaire to assist in the diagnosis of FAS. The results allowed for the creation of a developmental/ neurological profile. Numerous previous researchers have demonstrated intellectual deficits in children with FAS, the average IQ being in the borderline range (70-79). However, the neurodevelopmental profiles of infants have not been well studied.

Method: After examination by clinicians and establishment of a diagnosis of either FAS, Deferred or not FAS infants were evaluated by developmental/ neurological testing. Two hundred and sixty two infants between 9-11 months were tested using the Griffiths Scale of Mental Development which assesses the child's abilities in several separate domains namely: Locomotion, Personal/social, Speech/Hearing, Eye-hand co-ordination and overall performance thereby providing a developmental quotient.

Result: The results show that the group of infants with FAS display a broad range of deficits in their developmental functioning compared to those with a normal diagnosis. All of the FAS-diagnosed infants performed below the developmental quotient or within the average range. Locomotion, eye-hand coordination and general performance scales were found to be especially poor.

Conclusion: We can contend that certain key developmental/ neurological aspects are implicated in FAS infants. However, developmental standardization criteria for the whole population of De Aar would be a

valuable comparative tool. Assessing and diagnosing FAS during infancy, allows for appropriate interventions, thereby decreasing the severity and number of secondary disabilities at a school level.

Differentiating Between Autism Spectrum Disorders And Other Developmental Disabilities Using The Modified Checklist For Autism In Toddlers (M-CHAT)

Authors: *P. Dixon, J. Pandey, J. Kleinman, H. Boorstein, S. Allen, L. Wilson, E. Esser, T. Dumont-Mathieu, M. Barton, J. Green, G. Marshia, D. Fein*

Background: The early detection of autism is critical for early intervention and therefore optimal prognosis. The Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 2001) is a parent-report checklist designed to detect Autism Spectrum Disorders (ASD) in 16-30 month old children.

Method: To date, 2,570 children have been screened by either their pediatrician or early intervention provider. Those who failed the screening and a telephone follow-up (n= 163, mean age = 22 months) were evaluated.

Result: One hundred and twenty children were diagnosed with ASD and 36 with language or global developmental delay. The other 7 children were eliminated from the following analyses because of a unique diagnosis (e.g., 1 ODD, 1 ADHD). Previously published results by Robins, et al. (2001) analyzed screening items that differentiated the ASD children from the total screened non-autistic population, most of whom were typically developing. The current sample of non-autistic evaluated children is now large enough to compare to the ASD children. Percent failure rates will be presented for each diagnostic group for each of the 23 M-CHAT items. Using chi-square test, significantly more of the children diagnosed with ASD failed items: pointing to show interest, $p < .001$, responding to name, $p < .005$, pointing to request, $p < .01$, following a point, $p < .01$, taking an interest in other children, $p < .05$, understanding what people say, $p < .05$, and appearing deaf, $p < .05$.

Conclusion: These items that discriminate between the ASD children and the children with language delay or global developmental delay largely overlap with the items identified as most critical in distinguishing ASD from normal development. Therefore, these items can differentiate ASD children, not only from typically developing children, but also from children with other early manifesting developmental disabilities.

Public Health Implication: The M-CHAT can be used to screen for ASD in typically developing children as well as in children with other developmental delays.

Direct Service Staff Turnover in Private Sector Corporations Serving Persons with Developmental Disabilities

Authors: *S. Seninger, D. Bainbridge, M. Traci, T. Seekins*

Background: Individuals with disabilities are at increased risk for preventable health problems, or secondary conditions, that are costly to both the individual and society. As many adults with DD are living in supported environments, someone else is primarily responsible for organizing the environment and ensuring healthy behavior patterns. Our research has begun to describe a positive relationship between the experience of PA turnover and the experience of more limitations due to secondary conditions and higher rates of health care utilization

Method: A corporation questionnaire on direct service staff turnover was mailed to administrators of 33 Montana private service corporations that offer adult DD services with 14 corporations responding (42% response rate). Reported corporation characteristics included: location and geography, workforce size, budget, number and disability of clients served, direct service staff turnover rates, costs associated with turnover (hiring, vacancy replacement, and training costs). The reported corporation wage levels, turnover rates, and costs of turnover were compared to labor market employment and wage levels with a focus on urban and rural differences.

Result: Turnover rates of full- and part-time workers for a three-month period were lower in rural (4%, 18%) versus urban (17%, 20%) corporations. Costs of turnover per exit (i.e., hiring, vacancy replacement, and training costs) averaged $1,693 for urban corporations and $1,441 for rural corporations. Wages for direct service and managerial staff who provide some direct service ranged from $6.00 to $11.60 in rural areas, and $6.50 to $12.32 in urban areas. The insignificant difference in range ($.50 - $.72) did not accommodate for varying costs of living in the urban versus rural setting.

Conclusion: Lower wages for direct service staff in both urban and rural areas challenge the corporations. Area costs of living and rates of unemployment create additional economic competition. High turnover rates for full and part-time staff directly impact the stability of the consumer environment, and negatively impact organizational budget and coherence.

Public Health Implication: Turnover of direct service staff is an issue for many segments of the service delivery system. Turnover has a significant impact on corporation costs and organizational stability. The effects of turnover are further reflected in consumers served by increased limitation due to secondary conditions, or greater utilization of the healthcare system. Documentation of actual and human costs, and identification of factors that influence turnover can inform methods to reduce turnover by addressing both the economic and the staff environment.

Disability and Public Health Project: Creating A Curriculum

Authors: *C. Drum, G. Krahn, B. Ritacco*

Background: An important responsibility of the academic discipline of public health is to develop and translate new knowledge to the future public health workforce. Yet academic public health has been slow to incorporate disability into its research and curricular offerings. When included, the traditional focus is on primary prevention of disabilities and excludes addressing the health of people living with disabilities. A revised paradigm of disability is manifest in the ICF, which focuses on understanding the impact of environmental barriers to the disabling process. This legitimizes the inclusion of disability within public health. The goal of the Disability and Public Health project was to develop a curriculum on contemporary perspectives and issues of disability for MPH students.

Method: The project used an extended focus group method with diverse experts (faculty with significant disabilities, a public health ethicist, a state public health officer, an epidemiologist, a psychologist, an associate provost for diversity, a special education faculty member, and two disability policy faculty) to determine curriculum topics and assign primary and secondary authorship. Following initial chapter development, the group reconvened with faculty from two other public health programs as potential teachers of the course. Discussion focused on continuity, comprehensiveness, and comparability of format. The seminar is taught annually at OHSU.

Result: Course content includes: Disability Models and Approaches; A History of Public Health; Disability Epidemiology; Multicultural Views of Disability; US Disability Policy, Programs and Services; Personal and Contemporary Experiences of Disability; Health Promotion and Disability; Public Health as Change Agent for Disability. The course has been positively received by students and is now integrated into OHSU's MPH program.

Conclusion: Inclusion of a contemporary disability perspective in an MPH degree via a disability and public health curriculum has viable state and national support. Student feedback suggests that the content areas are appropriate and relevant, although continued refinement and implementation of the curriculum is warranted.

Public Health Implication: Incorporation of disabilities into the realm of public health practice requires that students in public health programs receive training in issues relating to disabilities. This integrated curriculum serves as a resource for academic public health programs to use the course materials in their modular format or in its totality. Through examples and exercises that use core public health approaches and disability data, public health students become more aware that health disparities exist between people with and without disabilities, the role of environments to disabling or enabling persons with functional limitations, and strategies for intervention.

Do Pediatric Residents Know the Five Areas of Development?

Author: *M. Pavan*

Background: Developmental pediatrics has expanded quickly in the last ten years with the implementation of the Part C Program of the Individuals with Disabilities Education Act. Families and professionals in every community need information about early childhood development in order to identify and provide services appropriately. Even though pediatric residents provide specialty care for infants and toddlers, it is anticipated that residents have gaps in knowledge about early childhood development. A recent survey of the AAP Project Advisory Committee for Medical Home Initiatives for Children with Special Needs indicated that 46% of pediatricians lack understanding of the Early Intervention (EI) program processes and services.

Method: From 1995 to 2003 during the first week of the month long rotation in developmental pediatrics, 64 pediatric residents were asked by one physician to write the five areas of development that the Part C Program is required to evaluate for each child. The information was scored after the resident completed the task. The five areas were physical (fine and gross motor), cognitive, communication, social or emotional, and adaptive (self-help).

Result: Only 8% of residents listed the 5 areas accurately, 34% listed 4 areas, 44% listed 3, and 14% listed 2. Residents always listed physical (or motor): 100%. However, they often listed fine motor and gross motor skills as two separate areas. Because they were counted as one, the resident listed no fifth area. Communication (language, or speech) was listed 95% of the time. Cognitive was listed 58%, social 60%, and adaptive 9%.

Conclusion: These pediatric residents did not know the five areas of early childhood development until the pediatric development rotation. It was apparent that during their residency training, these residents had not learned about Part C and the five areas of early childhood development. Because the Part C program began only 10 years ago, many pediatricians in practice have not had the opportunity to train in the developmental programs. It is anticipated that practicing pediatricians, like pediatric residents, think in a medical model of physical, occupational, speech therapy rather than in an early childhood model of specialized teaching and coaching parents to use daily routines to practice skills and to imbed social, adaptive, and cognitive problem solving skills with language and physical skills.

Public Health Implication: Physician education about the five areas of development continues to be needed. Specialized teachers should be encouraged to send reports to physicians to share their objectives and methods. Services will improve for children and families when pediatricians and professionals promote learning in all five areas of development in daily routines where children live, play, and learn.

Down Syndrome Prevalence In Hungary After The Chernobyl's Nuclear Power Plant Accident

Authors: *J. Sandor, J. Metneki, M. Szunyogh, C. Siffel*

Background: The only positive result of earlier Hungarian teratological investigations on consequences of the nuclear power plant accident in Chernobyl was the description of increased prevalence of birth with less than 2500 grams body weight. It was attributed to the concern of the pregnant women, not to the direct effect of ionising radiation. The role of the accident could not been excluded unambiguously in the increase of Down syndrome prevalence in Hungary. This study aimed to refine the earlier results by application of sensitive epidemiological techniques.

Method: The within Hungary geographical pattern of post-accident increase of background level of ionizing radiation was determined and all the 150 districts of the country were described by average accident-related doses. Utilizing the dataset of the Hungarian Congenital Abnormality Registry, the empirical Bayes-adjusted and district-specific Down syndrome prevalence ratio were computed for different time periods (1980-1985, 1986-1988, 1989-2001; before, around and after accident). The geographical pattern of exposure and Down syndrome prevalence were correlated.

Result: There was no geographical association between the exposure and Down syndrome risk in any study period: r1980-1985 = 0.019 (p = 0.821), r1986-1988 = 0.077 (p = 0.351), r1989-2001 = 0.038 (p = 0.648). The change of district-specific Down syndrome risks by time period was also analyzed in relation to the exposure, showing negative correlation (r1986-1988/1980-1985 = 0.061; p = 0.458 and r1986-1988/1980-1985 = 0.016; p = 0.842).

Conclusion: The ecological investigation of geographical inequalities did not show a correlation between the Chernobyl-related exposure and Down syndrome prevalence in Hungary.

Public Health Implication: The results supported the earlier conclusions of the studies that the Chernobyl accident caused no detectable increase in the prevalence of Down syndrome. The methodology can be applied to analyze associations between the prevalence of other congenital malformations and environmental exposures in small areas. The importance of risk communication in prevention of psychologically-based health impairments is also underlined by our observations.

Early Hearing Detection and Intervention (EHDI) Storyboard: An Example of Educational Materials for Families of Infants with Hearing Loss

Authors: *K. Biernath, J. Holstrum, M. Adams, L.A. Ramsey, M. Victor, D. Ross*

Background: When an infant is diagnosed with hearing loss (HL), parents are often overwhelmed with information. Likewise, the information provided to parents about the array of communication options available is not always balanced and comprehensive. The objective of this project was to produce an educational product addressing these issues.

Method: The creation of the EHDI storyboard was a two-step process. First, eight qualitative telephone interviews were conducted to gather recommendations from parents and professionals for the initial draft storyboard. Second, a five-part, year-long review of the storyboard was conducted. Each iteration was reviewed by 5 to 10 professionals, parents, or advocates representing diverse areas of expertise and experience to ensure a balanced product. Editing occurred after each review. An outside contractor is currently packaging the storyboard into a user friendly format. A prototype of this format will be presented.

Result: Based on reviewer feedback, the storyboard evolved from a one-part document into a three-part document that included balanced information on intervention strategies, communication options for infants with HL, and the family decision-making process. An emphasis was placed on balancing information on communication options in an easy-to-understand "building block" format.

Conclusion: A systematic, intensive review process by parents, professionals, and advocates involved in EHDI is one method for developing educational materials that are relevant and balanced. Next steps include finalizing the packaging, dissemination, and evaluation of the product. Also, a Hispanic version of the storyboard is now being created.

Effect of a Social Marketing Campaign on African-American Women's Knowledge of Fetal Alcohol Syndrome (FAS)

Authors: *M. Mengel, M. Ulione*

Background: The purpose of this study was to develop, implement, and evaluate a media campaign to improve knowledge and attitudes about Fetal Alcohol Syndrome (FAS) in African American women of childbearing age. The media campaign was built around four core messages: 1) A description of the effects of FAS and the fact that these effect occur early in pregnancy, often before women even know they are pregnant, 2) If pregnant, women should totally abstain from drinking alcohol, as there is no "safe" level of drinking, 3) In order to decrease the risk for FAS women should not engage in "at risk" drinking if they are sexually active and there is a possibility they could become pregnant, and 4) Women who feel their alcohol use may place them at risk for FAS should get an assessment and treatment recommendation from their physician as soon as possible.

Method: This was a quasi-experimental design in which knowledge and attitudes were assessed before and will be assessed after our intervention in St. Louis and a control community in Kansas City. Through a random digit dial survey of select numeric prefixes, 799 African American women between the ages of 18 and 35 were given the pre-intervention survey. This was followed by an 18-month media campaign. In April 2004, a random digit dial post-intervention survey will be conducted in St. Louis and Kansas City.

Result: The pre-intervention survey data indicated that the mean knowledge score of all women was 5.8, compared to an ideal score of 10, indicating knowledge gaps exist regarding FAS. Further data analysis demonstrated that non-drinkers, non-smokers, those with high income, and those who had early prenatal care had significantly higher knowledge scores than drinkers, smokers, those with low income, and those that had no prenatal care.

Conclusion: The post-intervention survey data will determine the efficacy of the campaign in improving knowledge and attitudes about FAS. Current data suggests that certain women need more education than others.

Public Health Implication: Fetal Alcohol Syndrome is completely preventable if women do not drink during pregnancy. Pre-intervention survey data suggests that there are considerable knowledge gaps about FAS in African American women in their childbearing years. This study will also demonstrate if a media campaign can be designed in a culturally competent fashion to reach an "at risk" population.

Effect of Brief Physician Counseling on Women's Use of Folic Acid Supplements

Authors: *J. Robbins, M. Cleves, H. B. Collins, N. Andrews, L. Smith, and C. Hobbs*

Background: Less than a third of women of reproductive age in the U.S. take folic acid on a daily basis. Many women state that they would be willing to take folic acid if encouraged to do so by their physician. This randomized trial tested this assertion by comparing the impact of brief physician counseling about the benefits of regular folic acid use during the routine gynecologic visit on daily and weekly intake of folic acid supplements.

Method: Women seeking routine gynecologic care from 4 clinics were randomized to receive either a brief (less than 1 minute) physician counseling message about folic acid and a complementary starter bottle of 20 folic acid tablets (n = 160), or a brief physician counseling message about sunscreen use, breast self-exam, or seatbelt use (n = 162). Folic acid use was determined before the intervention and 2 months following the intervention by self-report.

Result: No significant differences were found between groups in increased daily intake of folic acid. Women in the folic acid counseling group increased their weekly intake of folic acid by 68% (from 40% to 64%) compared to women in the control group who increased their weekly intake by 20% (from 34% to 51%) ($p < .001$). In subgroup analyses, African American women increased their weekly intake by 105% (from 30% to 61%), approximating the post-intervention weekly intake of white women (70%).

Conclusion: A very small investment of clinic time can substantially increase the number of women using folic acid on a regular basis. Because most women capable of becoming pregnant regularly see their gynecologist for health maintenance visits, gynecologists can have a substantial impact on reducing the incidence of folate-preventable birth defects.

Public Health Implication: The rate of daily folic acid use has remained largely unchanged over 7 years despite an aggressive national educational campaign. More than two-thirds of women of reproductive age do not take folic acid daily as recommended. Renewed efforts should focus on physicians and nurses as the conduit of information on the benefits of folic acid with the goal of regular if not daily use of a folic acid supplement. When given a clear message by a respected health care provider, women may move toward the target of daily folic acid use.

Effectiveness of Early Intervention with Children Prenatally Exposed To Cocaine: Replication with Multiple Cohorts

Authors: *K. Bono, L. Bolzani Dinehart, A. Claussen, K. Scott, P. Mundy, and L. Katz*

Background: Children who are prenatally exposed to cocaine are at-risk for cognitive, language, and behavioral developmental delays and represent an early identifiable group that may benefit from early intervention services. Results from the first cohort of the Linda Ray Intervention Program (LRIP) demonstrated that three levels of early intervention differentially prevented developmental delays in a group of infants prenatally exposed to cocaine. Specifically, center and home based intervention improved outcomes at age 3 compared to primary medical and social services, with center based services resulting in the most optimal outcomes. The purpose of the current study was twofold: (1) to replicate and (2) to expand on this finding by demonstrating its effects over two additional cohorts of participants.

Method: The LRIP consisted of three levels of intervention (1) Center-based, i.e., child-focused center-based intervention for five hours a day, five days a week, (2) Home-based, i.e., 2.5 hours of child-focused teacher home visits each week, and a Primary Care comparison group. All three groups received coordinated medical and social work services. Children were primarily enrolled in the first year (median age=5.8 months) and assessed at 36 months. Participants included 342 primarily minority, low SES children who participated in the LRIP between 1991 and 2003. Measures included cognitive ability, language ability, behavior problems and prosocial behaviors. A composite problem behavior score was created from the CBCL and the ASBI disrupt scale.

Result: There were statistically significant intervention effects for cognition, $F(2, 282) = 7.25$, $p=.001$; language, $F(4, 542) = 3.66$, $p < .01$; and behavior problems, $F(2, 252) = 2.42$, $p < .10$, but no significant effects for prosocial development. Compared to Home-based, Center-based participants had higher expressive language, $t(223) = 2.74$, $p < .01$, and receptive language, $t(223) = 1.89$, $p < .10$. Effect sizes for the significant effects ranged from .16 to .65.

Conclusion: These findings indicate that the LRIP Center and Home-Based Interventions had a positive effect on cognitive, language, and behavioral development.

Public Health Implication: The results of this study suggest that early intervention programs targeted at children who are at-risk due to biological and environmental factors can be sustained over time and may be a feasible way to prevent developmental disabilities at preschool age.

Effectiveness of Preschool Screening In Identifying Children with Disabilities

Authors: *C. Delgado, S. Vagi*

Background: Early identification has become recognized as a necessary tool in providing the most effective intervention services to children with disabilities. While the effectiveness of early intervention programs has received a good deal of attention, much less attention has been paid to preschool screening programs. This study evaluated the efficacy of the preschool screening program used in Florida to identify children with disabilities.

Method: The sample consisted of 11,384 children (7,178 boys) who were born in Florida, screened for a disability when they were 3 or 4 years-old, and had outcome disability data available at 3rd, 4th, or 5th grade from the 2001-2002 Florida public school records. Children were categorized into three groups based on the outcome of preschool screenings and their preschool disability status. Children in the Pass Screening No Disability (PND) group passed the preschool screening and did not receive further evaluation. Children in the Fail Screening No Disability (FND) group failed the preschool screening, received further evaluation, and were determined ineligible for special education services. Children in the Fail Screening Disability (FD) group failed the preschool screening, received further evaluation, and were determined eligible for special education services.

Result: The proportion of children with an outcome disability was 17.9% for the PND group, 37.6% for the FND group and 65.0% for the FD group. The majority of children in the PND and FND groups who had an identified outcome disability were specific learning disabled (46.1% and 37.0%, respectively) or speech/language impaired (26.6% and 31.5%, respectively). Of the children in the FD group who did not have a disability at outcome, 73.6% were identified with speech/language impairment as preschoolers. This study revealed an overall sensitivity of 86.5% and a specificity of 87.7% for the Florida screening program.

Conclusion: The screening program used throughout Florida is doing an effective job of identifying children who need special education services. Efforts to improve early identification should focus on preschool children who failed screenings but were not identified with a disability. Over one-third of these children were enrolled in special education later in elementary school. Early identification and service provision undoubtedly played an integral role in the shift from special education to regular education for the 35% of children who were identified with a disability as preschoolers but not at outcome.

Public Health Implication: Accurate early identification of children with disabilities and subsequent early intervention will minimize associated negative effects and improve child outcomes.

Effectiveness of Several Interventions and Reinforcement on Oral Health of Persons with Intellectual and/or Developmental Disabilities

Authors: *D. Bainbridge, M. Traci, T. Seekins*

Background: Dental problems are among the top 10 secondary conditions that limit participation in adults with developmental disabilities (DD). Etiology and severity of DD, as well as age and living arrangements, affect oral health. More untreated caries and higher rates of gingivitis are reported in adults with DD. This research explored strategies for managing oral health behaviors with low cost and health promoting outcomes.

Method: Twelve adults with DD from supported living situations volunteered for participation. Participants, working with personal or peer support, used one of three randomly assigned devices (double-headed brush, rotary brush, or sonic brush) on one side of the mouth. The control device was a manual brush used on the other side. A dental hygienist, blind to intervention, used the Oral Hygiene Index (debris and calculus), the Lobene Stain Index, and the Gingival Index before and after intervention to assess risk for dental disease. Participants responded to surveys assessing brushing behavior and self-efficacy. Personal/peer supports delivered prompts once daily and verbal reinforcement bi-weekly, and they logged the type, length, and frequency of prompts.

Result: Post-intervention, improvements on the oral health indices were observed in all participants (LSS, p=.007; OHI debris p=.095; GI, p=.000), regardless of

brush type as indicated by oral health composite change scores (Double-headed, M = -1.50 (SD = .86); Rotary, M = -1.22 (SD =.56); and Sonic, M = -.75, (SD =.59)). Although Consumers preferred mechanical brushes initially, they had no clear preference at the end. Personal/peer support logs reflected an average cost of $5.04 per month (range = $.29 - $23.38) for prompts and reinforcement based on state salary ranges .

Conclusion: Regular brushing maintained by minimal support reduced plaque and gingivitis in these adults with DD. Participants had no strong preference for mechanical versus manual brushes. These preliminary results suggest that the intervention is a low cost and effective means to improve oral health behaviors in adults with DD.

Public Health Implication: Good oral health behavior is a goal for consumers with DD, although little is known about recommended types of brushes and behavior. These results are relevant for many populations that require ongoing support to maintain good oral health to prevent the need for more invasive and expensive oral care.

Efficacy of OAE/ABR Protocol in Identifying Hearing Loss in Newborns

Authors: *J. Johnson, K. White, S. Meyers, J. Widen, Y. Weirather, J. Gravel, A. Maxon, L. Spivak, B. Vohr, M. James-Trychel, M. Sullivan-Mahoney, T. Kennalley, K. Biernath, L. Ramsey, J. Holstrum, and B. Culpepper*

Background: Results will be presented for a research study of the efficacy of the two-stage newborn hearing screening protocol in identifying hearing loss. This protocol was recommended by the NIH Consensus Statement in March 1993. This study was funded by the Centers for Disease Control and Prevention to determine whether this protocol was missing babies with a significant hearing loss.

Method: The study enrolled 1,557 sample babies out of a birth population of 88,252 babies, from 12 birthing centers over a 21-month period. Detailed neonatal, perinatal, risk-data, and socio-economic indicators were obtained for each enrolled baby. Audiological diagnostic evaluations were completed for as many of the 1,557 babies as possible when they were between 8-12 months of age. The detailed diagnostic protocol consisted of visual reinforcement audiometry (VRA), tympanometry, and evoked oto-acoustic emissions. In addition to the babies in the sudy, detailed enrollment and diagnostic data were obtained for a comparison group of all babies born during the same time period at the same hospitals who were referred for diagnostic audiological evaluations based on being referred on both the OAE and ABR screening.

Result: The analysis of the data was completed by the end of March, 2004. The study will answer the question of the prevalence of study infants with a permanent, congenital hearing loss, and also provide data about what proportion the babies in the study constitute of the total cohort of infants with a hearing loss.

Conclusion: The research results and case studies will be described and future research needs identified.

Public Health Implication: The results may result in changes in the recommended protocol for use in newborn hearing screening to assure that all newborns with a significant hearing loss are identified.

EHDI Legislation: A Tool for Ensuring Infants are Screened for Hearing Loss

Authors: *D. Green, M. Gaffney*

Background: Hearing loss is one of the most common birth defects identified in the newborn population; however when undetected it can lead to developmental delays in children. To help ensure that infants with hearing loss are identified as early as possible, 38 states (as of 2003) have passed legislation related to hearing screening. To help assess the impact of this legislation, the CDC Early Hearing Detection and Intervention (EHDI) program analyzed reported hearing screening rates to see if legislation had an impact on the percentage of infants screened for hearing loss.

Method: Data reported to the Directors of Speech and Hearing Programs in State Health and Welfare Agencies from calendar years 2000 through 2002 were used to ascertain hearing screening rates. To determine which states had passed legislation, a review of annual state reports, cooperative agreement applications, and relevant organizational websites was conducted during fall 2003. Following identification of states with hearing screening legislation, a detailed review, including associated rules and regulations (if applicable), was conducted to abstract specific information about requirements related to the date of implementation and data reporting. This process included contacting state EHDI personnel to confirm preliminary abstracted information.

Result: Initial results indicate that states with hearing screening legislation reported statistically significant higher screening rates in each study year (2000-2002) compared to states without legislation. Due to small sample size, results were inconclusive regarding the effect of specific legislative requirements (e.g., mandated data reporting to a state health department).

Conclusion: Overall, preliminary results indicate that state legislation related to hearing screening is associated with higher screening rates. States with lower rates of screening before the implementation of legislation reported notably higher screening rates following its implementation. Based on this, legislation appears to be related to higher rates of hearing screening in states.

Public Health Implication: Based on preliminary findings, legislation may be one tool states can use to help ensure a greater percentage of infants are screened for hearing loss.

Epidemiology of Autism Among California-Born Twins

Authors: *J. Grether, M. Anderson, B. Hopkins, L. Croen, P. Choate, R. Huff*

Background: Autism is a relatively common cause of life-long disability, thought to be occurring in up to 6/1,000 American children, but non-genetic contributions to the etiology of this condition are currently unknown. The descriptive epidemiology of autism in twins will provide a framework from which to design further studies to evaluate hypothesized non-genetic risk factors.

Method: From among the autism population enrolled with the California Department of Developmental Services (DDS), we have identified >400 twin pairs born 1987-1998 in which one or both members of the pair are diagnosed with autism. The electronic client records on these twins have been individually linked to their birth certificates to identify births to California residents and to obtain demographic variables. To describe and interpret the epidemiologic characteristics of these twins with autism, we have constructed multiple comparison groups: twin pairs enrolled in DDS with mental retardation of unknown etiology without autism (N=719), all live born twins (N=140,656), all twin pairs/pregnancies (N=70,328), and all live born singletons (N=6,000,000). Variables considered include maternal and paternal age, education, and race; infant gender, birth weight, and birth order; length of interval since last live birth; parity; and twin concordance in DDS for autism.

Result: The large number of twins in this population-based series permits an evaluation of the epidemiology of autism among twins with a high level of statistical precision. Univariate and multivariate data will be presented from the most informative comparisons to evaluate possible etiologic clues.

Conclusion: Conclusions will be presented based on study results.

Epidemiology of NTD Cases Four Years After A Folic Acid Campaign In Nuevo Leon Mexico

Authors: *L. Martinez, P. Arredondo, R. Hernandez, J. Villarreal*

Background: The epidemiology of NTDs depends on genetic, nutritional and environmental factors. Its prevalence is higher in some ethnic groups, and there is an association with folate deficiency and folate related genetic polymorphisms in mothers and in fetuses. Preconceptional folic acid (FA) is known to prevent NTDs although the size of the effect for a given dose is unclear. Anencephaly cases are more common, mainly in female products. In August 1999, a FA campaign was started in Nuevo Leon, a state in northeast Mexico, with the recommendation of taking a 5-mg tablet per week. The goal of this study was to compare the prevalence, phenotype and sex ratios of infants with NTDs before and after the FA campaign.

Method: NTD (anencephaly, spina bifida and encephalocele) cases were registered by immediate notification, death certificates and fetal death registries. NTD rates, phenotype, and sex ratios, before and after the FA campaign, were compared. Maternal reproductive antecedents, scholarity and socio/economical status were also compared. Data were analyzed using the Student t Test and X2 Test.

Result: There was a marked fall in the incidence of NTDs, from 95 cases (1.04 x 1000) in 1999 to 52 in the year 2003 (0.56 x 1000). The highest reduction of spina bifida (SB) cases was observed in the year 2002 (68%) and for anencephaly cases in the year 2003 (50%). In 1999, overall, the ratio (females: males) was 0.66 with female excess. Sex ratio by NTD phenotype was similar, 0.62 and 0.65 for anencephaly and SB cases respectively. In the year 2000, sex ratio was 0.57 with

a greater male excess for both phenotypes. Female cases showed a significant reduction (SB 75% and anencephaly 56%) while male cases increased. During the last three years, sex ratios were close to unity. Incidence rate was higher in rural than urban area. We did not find differences in maternal age, scholarity, occupation (almost all were housewives) or exposure to other risk factors such as use of contraceptive pills, anticonvulsant drugs, or maternal illness. A seasonal incidence variation was observed.

Conclusion: Our results indicate that the weekly administration of 5-mg of FA reduces the incidence of NTDs by 50 %, mainly SB, with a higher reduction of female cases. The epidemiology of NTDs may be modified after a folic acid campaign.

Public Health Implication: Public Health Implications: Weekly administration of a high dose of FA could be an easy, low cost and effective public health strategy to reduce the incidence of NTDs.

Establishing A Prevalence Rate for Krabbe Leukodystrophy

Authors: *M. Gartzke, A. Rugari*

Background: Krabbe Leukodystrophy is associated with significant morbidity and mortality. Children with the infantile form have rarely survived beyond 2 years. Cord blood transplants have recently made a significant impact on the lives of Krabbe children transplanted before 2 months of age. The Hunter's Hope Foundation has a newborn screening task force to collect data required by individual states to implement newborn screening.

Method: A web-site (www.krabbes.com) was established to collect demographic information on affected children. This web-site was available for data entry from April 2001 to April 2002. There were no restrictions on age or year of diagnosis. Data collected from the web-site included the birthplace, date of birth (and death if applicable), and current residence of family. This information was also collected for the mother and father. Only numbers for children born in the year 2000 were included in this study.

Result: The web-site indicated that there were at least 12 children born with Krabbe in the US in the year 2000. Data on 54 children who have been diagnosed with Krabbe, but are missing specific information about their birthplaces and date of birth were excluded. The 12 children were born in CA, IL, KS, ME, NV, NY, OH, TX, and WI. The total number of births in those states in the year 2000 was 1,648,042. Resulting in a combined prevalence of Krabbe in those states of at least 1:137,336. This number does not and can not take into account Krabbe children born in the US, but not entered into the web-site. The states where the majority of children born with Krabbe are WI, NY, MN, and MI. Interestingly, these states have a significant number of residents who are of Swedish descent (in Sweden, the prevalence rate is 1:25,000).

Conclusion: This data demonstrates that although Krabbe Leukodystrophy is a rare disorder, it is prevalent enough to be considered for newborn screening.

Public Health Implication: With the advent, advances and cost effectiveness of MS/MS in identifying diseases with prevalence rates similar to Krabbe Leukodystrophy, combined with the significant impact that Cord Blood Transplants have provided to children that born with Krabbe Disease, the public health implications are many more children's lives will be saved, and families can be spared the immeasurably significant negative economic, social and emotional costs that accompany the unnecessary death of a child born with Krabbe Leukodystrophy.

Evaluation of Ascertainment Sources For Fetal Alcohol Syndrome (FAS): What Combination Results In The Greatest Yield?

Authors: *D. Fox, C. Druschel*

Background: Surveillance for fetal alcohol syndrome (FAS), a preventable birth defect resulting from heavy maternal alcohol use, is challenging, with advantages and disadvantages to each surveillance strategy. Between states and even within states, programs and resources to identify suspect children vary tremendously. One goal of the Fetal Alcohol Syndrome Surveillance Network (FASSNet), a population-based, CDC-funded cooperative agreement funded in 1997, was to evaluate ascertainment sources.

Method: Using FASSNet data for western New York, we evaluated our FASSNet surveillance system by ascertainment source on order to develop the most efficient surveillance methods

Result: For birth years 1995 to 1999, 832 children were identified who were born in the surveillance region. Seventy-eight of these children represented FASSNet

cases and 56% were identified by more than one ascertainment source. The best source types were Genetics and Developmental Programs, referring 15% of all children and 69% of all FASSNet cases. Identification of a suspect child with an ICD-9 code of 760.71 by any source was also fairly effective, with 8% of children referred and 38% of FASSNet cases identified by this method. Early Intervention Programs were not as effective at referring children that would be FASSNet cases, with 14% of children referred but only 15% of all FASSNet cases. This source did identify 4 children that would not have been identified by other methods. Use of hospital discharge codes to identify high-risk pregnancies was effective (31% of the FASSNet cases identified by this method) at identifying FASSNet cases but not efficient because of the large number of children/births identified (n=467). Only 5% of children identified by this method were FASSNet cases, and all but 2 children were identified by other sources.

Conclusion: Almost 95% of FASSNet cases were identified through Genetics, Developmental or Early Intervention Programs or with the ICD-9 code 760.71. Restricting surveillance efforts to these sources/methods would have reduced the total number of children identified by 68% (563 fewer children) and saved us approximately 900 hours in abstracting time. FAS remains a challenging syndrome to recognize. Surveillance systems that include specialists trained to recognize FAS remain the best sources for inclusion in surveillance efforts.

Public Health Implication: Evaluation and communication on the effectiveness and efficiency of different FAS surveillance methods will improve surveillance practices in other states and result in an improved capability to accurately estimate the prevalence of FAS nationally.

Evaluation of Early Hearing Detection and Intervention-Michigan, 1998-2002

Authors: *D. El Reda, V. Grigorescu, A. Jarrett, C. Miller*

Background: Hearing loss (HL) is a commonly occurring congenital anomaly: approximately 8,000–16,000 of the infants born annually in the United States have a certain degree of HL. Early detection and intervention can improve the development of language and cognitive skills; thus, the Michigan Department of Community Health began an effort to universally screen newborns in 1998 through the Early Hearing Detection and Intervention (EHDI) program. The objective of this study was to determine whether EHDI has improved screening and referral rates, age at diagnosis, and timely enrollment into early intervention services.

Method: The 1998–2002 Michigan EHDI surveillance data were used to calculate screening and referral rates, prevalence of HL at birth, mean age at diagnosis, and enrollment into early intervention services.

Result: Screening rates have increased from 23.0% in 1998 to approximately 93.0% in 2002. Referral rates have declined steadily from 4.6% to 2.7% (potentially fewer false-positives). During this period, 1,101 cases (1.66/1,000 live births) of HL were identified, and the mean age at diagnosis decreased from 25 to 3 months. Since collection of follow-up data began in 2000, follow-up was reported for 350/597 (58.6%). Among these, 234 (66.8%) enrolled in at least one intervention service offered by the Department of Education. Enrollment of eligibles by 6 months of age increased from 43.4% in 2000 to 74.1% in 2002.

Conclusion: In Michigan, EHDI has improved early detection of HL at birth.

Public Health Implication: Sub-optimal follow-up reporting limits the ability to determine access to and participation in early intervention services. Collaboration and data sharing between public health agencies and the Department of Education are needed to improve follow-up.

Evaluation of the Metropolitan Atlanta Congenital Defects Program (MACDP)

Authors: *L. Williams, L. O'Leary, A. Correa*

Background: Surveillance methodology used by MACDP was developed in the late 1960s. The environment of birth defects surveillance has changed with the advent of prenatal diagnostic technology, increased availability of elective pregnancy termination, and greater concern for patient confidentiality. Additionally, the objectives of MACDP have expanded in recent years with the initiation of case-control studies and contributions to prevention education and health policy. To ensure that changes in the environment of birth defects surveillance have not compromised data integrity and system efficiency, an evaluation of the surveillance methodology was initiated.

Method: The evaluation methods used in this study are based on evaluation of surveillance systems guidelines published in a 2001 Morbidity and Mortality Weekly Report. The attributes of a surveillance system selected for evaluation were data accuracy, completeness, timeliness, and system simplicity. Evaluation methods for each attribute will be implemented in phases; Phase I of this evaluation focuses on data timeliness. Time from diagnosis/birth to abstraction was evaluated for cases from 1990 to 2000; data were stratified by year of birth, abstraction site, and defect group. Cases abstracted more than 1 year after diagnosis/birth were reviewed to identify patterns including defect type and pediatric care. Phase II of the evaluation will focus on system simplicity with regards to case finding and case processing; MACDP abstractors will record all data sources and abstraction criteria for potential cases reviewed at abstraction sites. Phase III will focus on data accuracy; including medical record reabstraction for a random sample of cases. Data completeness will be evaluated using hospital audits in Phase IV.

Result: 97.3% of MACDP cases are diagnosed within the first year of life. However, only 72.3% of cases are abstracted within one year of birth/diagnosis; 58.1% of cases are abstracted within 6 months. When data were stratified by abstraction source, 88.9% of cases from birth hospitals were abstracted in 1 year, while only 50.6% of cases from pediatric hospitals and 40.2% of cases from other sources were abstracted within 1 year. Cases abstracted after 1 year were more likely to have biliary atresia, hypospadias or epispadias, and limb reduction deformities; they were less likely to have an anencephaly, cleft lip/palate, intestinal atresia, and abdominal wall defects.

Conclusion: Reasons for the delay (>1 year after birth/diagnosis) in abstraction will be identified and changes will be made in an attempt to abstract 90% of cases within 1 year of birth/diagnosis. Phases II, III, and IV will be implemented and the results used to determine what modification may be needed to ensure data integrity and efficiency of the system.

Public Health Implication: Evaluation of MACDP is necessary to ensure that the system is able to effectively and efficiently meet its objectives. Results can be used to make improvements in timeliness, data quality, and simplicity. The evaluation process of planning and implementing their own evaluation plan.

Evaluation of the Reproductive Health Surveillance System In Haiyan County, People's Republic of China, 1993-2002

Authors: *L. Yeung, R. Ye, J. Gindler, Z. Li, R. J. Berry, J. Zheng*

Background: China reports a high maternal mortality rate (26/100,000 live births in urban areas to 308/100,000 in rural areas) that timely identification of high-risk pregnancies might help to reduce. Since 1993, Haiyan County has maintained a reproductive health surveillance system (RHSS).

Method: Using the Centers for Disease Control and Prevention surveillance system evaluation guidelines, we evaluated the Haiyan RHSS, including its recently implemented real-time electronic data entry format, which allows immediate generation of reports; the older, paper format allowed generation of reports only after pregnancy ended. Among all women, we compared percentages of missing values in key variables between the electronic and paper formats. Among women with and without high-risk pregnancies, we calculated rates of delivery in tertiary care hospitals and of Cesarean delivery.

Result: We found that the RHSS is estimated to provide 95% coverage among its target population. Two critical variables, date of last menstrual period and delivery location had very few missing values (<1.0% with paper format and <0.2% with electronic format). Women identified with high-risk factors in the third trimester delivered more frequently in tertiary care hospitals (risk ratio [RR]=1.63, 95%CI=1.17–2.28) and had more Cesarean deliveries (RR =1.37, 95%CI=1.33–1.41) than did women who did not have high-risk factors.

Conclusion: This active, population-based surveillance system is useful in identifying and referring high-risk women to tertiary care hospitals for delivery. Its newly implemented electronic data entry format ensures better data quality and allows data to be transformed into information more quickly.

Public Health Implication: A simplified version of this system should serve as a model to other developing countries.

Evidence on Effectiveness of Folic Acid Fortification: Results From a Systematic Review For the Guide to Community Preventive Services

Authors: *D. Hopkins, P. Nolan, J. Mulinare, S. Grosse, J. Sidhu, and the Folic Acid Intervention Review Team*

Background: The Guide to Community Preventive Services conducts systematic reviews of the literature regarding the effectiveness of population-based interventions to reduce morbidity and mortality. Folic acid fortification is the first intervention selected for review for the Community Guide chapter on interventions to improve maternal and infant health outcomes of pregnancy.

Method: A recruited team of public health experts selected the interventions for review. We conducted a systematic search using several electronic databases, and evaluated each intervention study for suitability of study design and quality of execution. Studies qualifying for inclusion in this review were summarized regarding the evidence on effectiveness, and on additional effects including potential benefits and harms. The independent, nonfederal Task Force for Community Preventive Services provides the final conclusions and recommendations regarding use.

Result: Ten qualifying studies from four nations (United States, Chile, Australia, and Canada) evaluated the effectiveness of folic acid fortification in reducing the prevalence of pregnancies affected by neural tube defects. In assessments conducted up to 4 years following fortification, reported prevalence rates of neural tube defects decreased in study populations in all four nations with estimates ranging from –0.88 cases per 10,000 live births to –14.1 cases per 10,000 births (relative percentage reductions of 23% and 54.6%, respectively).

Conclusion: Folic acid fortification was consistently associated with reductions in the reported prevalence rates of pregnancies affected by neural tube defects in four different nations.

Public Health Implication: Published studies demonstrate the effectiveness of folic acid fortification in reducing neural tube defects. Final recommendations from the Task Force will incorporate conclusions on the evidence regarding additional effects of fortification in the entire population.

Examining Variability in the Consumption of Medications Commonly used to Treat Attention-Deficit/Hyperactivity Disorder (ADHD): Regional Consumption of Methylphenidate and Amphetamine-based Medications, 1997 and 2001.

Authors: *C. Kennedy, C. Lesesne, A. Abramowitz, S. Visser*

Background: Researchers have suggested an increase in the volume of stimulant medications prescribed for the treatment of ADHD and regional variability of medication use (Cox, 2003). Little is known about specific medication consumption differences by region and what contributes to this variation in the U.S. Available data are limited in their generalizability and often include one medication (i.e. Methylphenidate) when several base formulas are highly prevalent (i.e. D-Amphetamine and DL-Amphetamine).

Method: Information on the cumulative consumption of the stimulant medications, Methylphenidate, D-Amphetamine and DL-Amphetamine (commonly used in the treatment of ADHD) were collected for the years 1997 and 2001 through the Drug Enforcement Agency's (DEA) system, Automation of Reports and Consolidated Orders System (ARCOS). These medications are schedule II controlled substances for which the government retains consumption data. Total consumption of the stimulant drugs (in grams per 100,000) were combined for each of the fifty states and for the District of Columbia for 1997 and 2001 and then placed into one of nine census regions. To account for regional and state differences in population characteristics, data were weighted using state-based intercensul population estimates.

Result: Comparison of the nine regions studied revealed notable variability between 1997 and 2001 between and within regions. The consumption per 100,000 after weighting the rates ranged in 1997 from 2575.4g (Mountain Region) to 4568.1g (WN Central); and in 2001 from 3819.5g (Mid Atlantic) to 6314.3g (New England). In addition to the increased consumption rates between 1997 and 2001, varied percent change in consumption rates over time were also noted in each region. The Pacific region experienced the lowest percent change with an 11.2% growth from 1997 to 2001, whereas the New England region experienced a 34.9% growth during this 5 year period (the greatest among all nine regions).

Conclusion: The inclusion of several forms of stimulant medications better reflects the total consumption nationally and suggests the need for further research.

Public Health Implication: The study results are important steps toward understanding potential factors influencing regional variation in stimulant-based medication use. Future public health research is needed to explore the recent increases and variation in consumption rates nationally.

Expanded Newborn Screening: The Mississippi Experience

Authors: *D. Bender, J. McClure, M. Zotti, T. Carey*

Background: Prior to 2003, the Mississippi State Department of Health (MSDH) conducted newborn screening for five conditions: phenylketonuria (PKU), hypothyroidism, galactosemia, congenital adrenal hyperplasia (CAH), and sickle cell. In March 2002 the Mississippi legislature passed a bill mandating the State Board of Health provide "comprehensive" newborn screening based on recommendations of the state Genetics Advisory Committee. This committee recommended adding cystic fibrosis, biotinidase deficiency, and an additional 33 conditions screened via tandem mass spectrometry—yielding a total of 40 conditions that are screened among newborns. The purpose of this paper is to describe the state experience in implementing expansion of newborn screening.

Method: Initial implementation steps included developing a national Request for Proposals (RFP) to select a laboratory, adopting a new fee schedule, creating procedures for follow-up of children with positive screens, creating health education materials, notifying hospitals and physicians regarding the change, and adding health department district level teams to case manage children with positive screens.

Result: Expanded newborn screening for 40 conditions began on June 1, 2003. A little more than four months into the expanded program MSDH identified children with: cystic fibrosis (n=2), biotinidase (n=3), galactosemia (n=1 and several carriers), TSH elevations (n=5), hemoglobinopathies (n=30), and possible propionic acidemia (n=1). New child health team MSDH district level positions for case management have been created and presently are being filled.

Conclusion: Mississippi now has one of the most comprehensive statewide newborn screening programs in the nation. The MSDH still has many ongoing issues to grapple with, such as appropriate follow-up for all abnormal test results and assuring appropriate referrals to physicians and family counseling.

Public Health Implication: A state level large-scale change in newborn screening requires a multi-faceted approach to assure protection of the public's health. This approach involves adequate resources (e.g., financial and health care system such as providers for referral), services and materials for parents, and health department structural changes to provide appropriate follow-up.

Expanding Newborn Screening Programs Beyond The World Health Organization (WHO) Criteria: The Cases of Fragile X and Duchenne Muscular Dystrophy

Author: *L. Friedman Ross*

Background: Universal mandatory screening programs developed in the 1960s to detect children with PKU in order to begin dietary treatment to prevent mental retardation. It expanded in the 1970s and 1980s to include other conditions for which early treatment prevented serious morbidity (e.g., mental retardation) or mortality. Today, more than 30 conditions are tested for in various states and around the world, and other conditions are up for consideration. Not all of these expanded conditions meet the traditional World Health Organization (WHO) criteria: that the condition be an important health problem that can be screened for pre-symptomatically with a simple test that is acceptable to the population, and for which a treatment exists. Two examples of conditions for which screening programs exist although the conditions have no preventative treatments are: Fragile X (a cause of mental retardation); and Duchenne Muscular Dystrophy [DMD] (a cause of progressive neurological weakness beginning in mid-childhood that eventually leads to respiratory failure and death).

Method: To examine the risks and benefits of expanding newborn screening to include these non-traditional conditions; 2) To consider what changes to the public health paradigm such inclusions would require; and 3) To become familiar oneself with lessons from newborn screening history: DMD [Wales], XYY [Boston], and Type 1 Diabetes Mellitus [Florida and Denver]. Finally, expanded newborn screening was examined in light of the alternatives: prenatal screening of women prior to conception and/or prenatal screening of the fetus.

Result: The expanded screening does not fit the public health model and requires informed parental consent. Such screening should be separated in time and place from traditional newborn screening in order to help parents understand the different values and goals of the different screening programs.

Conclusion: Expanded newborn screening for DMD can be justified. The arguments in favor of newborn screening for Fragile X are less compelling. I then consider what priority should be given to the expansion of screening programs for non-traditional conditions when screening for other conditions that meet the WHO criteria are not available to all.

Public Health Implication: As we expand newborn screening programs to include conditions that do not meet the WHO criteria, we will need to examine the implications of such a policy shift for public health, medicine, and the communities that we serve.

FAMILY MATTERS: Using Bright Futures to Promote Health and Wellness for Children with Disabilities

Authors: *B. Popper, B. Anderson, L. Pope, P. Minihan, A. Must*

Background: Family Voices and Tufts Medical School have developed a joint research study to determine effective strategies for health and wellness for children with disabilities, to help parents in their efforts to establish healthy habits when children are young and in their formative years. Due to advances in family involvement and medical care, the number of children with disabilities with virtually normal life spans has increased, creating an imperative to develop strategies to promote health and wellness among members of this group. Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents and Healthy People 2010 goals and recommendations guide this effort.

Method: The study has two hypotheses: 1) Bright Futures health and wellness recommendations for children are not always followed by families of children with disabilities; and 2) the receipt of peer support focused specifically on issues related to the health and wellness of children with disabilities and provided 1:1 by designated peer parents changes parents' implementation of health promotion habits. The study is employing focus groups, questionnaires and parent workshops to learn what families know, feel and do relative to Bright Futures advice. The study will use a randomized controlled study design to determine if families who receive peer support a) follow more healthy habits compared with control families and b) have different beliefs about the relevance of health and wellness recommendations for their children. The study will be implemented in five states with active Family Voices chapters, health departments and community pediatricians who have demonstrated interest in Bright Futures, and is guided by an active Advisory Committee.

Result: Year 1 activities include meeting with the Advisory Committee, training selected parent peer supporters to become focus group moderators, and conducting focus groups in five sites. By July, we will have information from Advisory Committee deliberations and focus group sessions about: a) how families of children with disabilities think about their child's "health," and the factors that may help or hurt it – now and in the future; b) the challenges families perceive in promoting healthier lifestyles and the kinds of assistance they think will help them overcome these challenges; and c) strategies that families have used to achieve successful health behavior change on their own.

Conclusion: Many of the nation's most prevalent chronic diseases affecting adults have roots in personal health behaviors. Helping families of children with disabilities promote healthier behaviors from childhood is an important but untested approach to assist people with disabilities to have healthier adulthoods.

Finding The Needle In The Haystack: Using A Touch Screen Computer System To Collect Low Base Rate Healthcare Utilization Information

Authors: *C. Ravesloot, C. Ipsen, S. Senninger*

Background: One of the challenges to achieving the gold standard of cost-effectiveness research (i.e. the societal perspective) is collecting complete information for all events to which costs should be applied. In healthcare research, this may include medical interventions and hospitalizations. Administrative data sets are commonly employed for tracking expenditures, but these data sets are incomplete. From a societal perspective, it is important to collect all costs associated with healthcare, not only those associated with delivery of medical procedures.

Method: Adults with mobility impairments who were recruited to attend an exercise program (n=208) used a

touch screen computer application called the Computer Assisted Healthcare Resource Utilization System (CAHRUS) to report healthcare services they had used during the previous seven days. The program queried participants about physician visits, emergency room visits, walk-in clinic visits, overnight hospital stays, therapies, diagnostic tests and surgeries. Additionally, the program collected time spent by the respondent and when needed, a personal assistant, to attend medical appointments. Validity coefficients were computed for a sub sample of Medicaid beneficiaries using Medicaid administrative reimbursement data and coded office visit notes from healthcare providers.

Result: Validity coefficients for CAHRUS ranged from .62 to .93 when the CAHRUS data was correlated with coded office notes and Medicaid administrative reimbursement data. Overall, during a two-year study period, respondents reported 807 physician visits, 43 emergency room visits, 67 walk-in clinic visits, 37 surgeries and 60 nights in the hospital. Collectively, respondents spent 2382 hours pursuing medical care and their assistants were included for 1516 hours of that time.

Conclusion: The touch screen methodology used for assessing healthcare resource utilization provided valid data. Hence, this study provides additional support for using self-report healthcare utilization strategies with a relatively short retrospective recall. Additionally, we were able to collect information about the amount of time study participants spent pursuing these medical services to include the societal perspective of a cost-effectiveness analysis.

Public Health Implication: The CAHRUS method may be instrumental for achieving the societal perspective in cost-effectiveness research. Additionally, touch screens used in a fitness or medical clinic environment hold promise for collecting accurate, low base rate information that is difficult to collect using long retrospective recall techniques.

First PAGE: A Strategy For Screening For Birth Defects and Genetic Disorders In A Primary Prenatal Care Setting

Authors: *E. Kloza, S. Ellingwood, J. Johnson, J. Haddow*

Background: Prenatal care providers (PCPs) are recognized as essential to the identification of pregnant women at risk of delivering children with birth defects or genetic conditions. Efforts to engage PCPs in genetic risk identification however, have had mixed success. Reported here is a strategy that has been used since 1996 to identify and manage women at risk while educating PCPs about genetic issues relevant to their practice.

Method: Dubbed ProgramME, the approach used a 15 element self-administered Genetic History Questionnaire (GHQ) indexed to a 15 section Office Guide, and was introduced in 1996 by project staff to 212 Maine PCPs. Eighty-five percent of survey respondents used the GHQ with all new patients and gave the approach a rating of 4.4 out of 5. The overall number of calls for genetic information or referrals for genetic services was unchanged following implementation of ProgramME. However, the percentage of calls initiated by family history increased from 13.2% to 27.4% ($p<0.01$), and calls associated with a maternal condition rose from 9.9% to 19.5% ($p=0.03$). Modified materials were introduced to an additional 7 diverse venues in the United States with similar success. In 2002, the March of Dimes funded a revision and update of ProgramME. At that time, 48% of Maine PCPs continued to use the 1996 ProgramME materials compared to 85% in 1996. Renamed First PAGE, the new materials were introduced to all Maine PCPs and mailed to all New Hampshire PCPs as well.

Result: Eighty-three percent of respondents to a survey of Maine participants intended to use the approach with all or most new patients, similar to the response in 1996. Seventy-one percent said First PAGE made them more confident discussing genetic issues with patients, and 69% said it simplified risk assessment. It helped 60% learn more about genetics, and assisted 74% in addressing risk early in pregnancy.

Conclusion: First PAGE is a well-accepted, useful, and important tool for engaging community PCP participation in risk identification and management, but must be introduced office by office by committed project staff to be integrated successfully.

Public Health Implication: Many of the opportunities presented by the Human Genome Project will be useful to the general population only if the primary care community can 1) determine which patients are at risk, 2) assess which tests or management protocols are appropriate, and 3) easily integrate genetics into their busy practices. First PAGE meets these needs for prenatal care providers and their patients.

Folic Acid Awareness, Knowledge and Use by Women of Childbearing Age in the United States - 1995-2003

Authors: *K. Green Raleigh, H. Carter, J. Mulinare, J. Petrini*

Background: National initiatives have been implemented to increase the use of multi-vitamins containing folic acid among women of childbearing age to reduce the risk of having a pregnancy affected by a neural tube defect. Identifying changes over time in women's awareness, knowledge, and use of folic acid since the implementation of national recommendations and mandates is an important step in directing future health prevention efforts.

Method: The March of Dimes contracted with the Gallup Organization to conduct random-digit-dialed telephone survey of a national sample of approximately 2000 women aged 18-45 years from selected years between 1995 and 2003. Statistical estimates were weighted to reflect the total population of women aged 18-45 years in the contiguous United States who resided in households with telephones. The margin of error for estimates based on the total sample size was plus or minus 2%. Results from the seven survey years are summarized.

Result: The percentage of women reported having ever heard of or having ever read about folic acid steadily increased from 52% in 1995 to 79% in 2003. Compared to 4% in 1995, 21% of women knew that folic acid prevented birth defects in 2003. The proportion of all women who reported taking a vitamin supplement containing folic acid daily remained essentially unchanged from 28% in 1995 to 32% in 2003. Of women surveyed in 2003, the percentage consuming a vitamin containing folic acid daily was lowest among non-white women (28%), women aged 18-24 (25%) and women who had less than a high school education (21%).

Conclusion: The steady increase over time among folic acid awareness and knowledge is encouraging. Nevertheless, results indicate that approximately 70% of women still are not taking a multivitamin containing folic acid daily despite national efforts to promote increased folic acid use. This study also suggests that among younger women, women of ethnic minority groups and women with less than a high school education consumption of a multi-vitamin containing folic acid daily is less than among other women.

Public Health Implication: Results from these seven surveys could be used to promote development and/or expansion of existing public health interventions targeting women of ethnic-minority groups and women of low education levels in promoting daily multivitamin consumption.

Folic Acid Use and Knowledge Among Women of Childbearing Age In Florida

Authors: *K. McDuffie, Y. Huang, M. Bailey, J. Correia*

Background: In 1992, the U.S. Public Health Service recommended that all women of childbearing age consume at least 400 µg of folic acid daily. To monitor supplementation and knowledge of the protective benefits of folic acid among women of childbearing age in Florida, the Florida Chapters of the March of Dimes provided funding to the Florida Department of Health to administer the Folic Acid module of the Behavioral Risk Factor Surveillance System (BRFSS).

Method: The Florida BRFSS is a state-based telephone surveillance system supported by the CDC. Using BRFSS data for 2002, the folic acid use and knowledge of women of child-bearing age (18-44 years) was examined.

Result: Preliminary analysis of weighted data reveals that 88% of women of childbearing age were supplementing their diets with folic acid. Those who supplemented tended to be over the age of 25, married, and have high school or higher level of education. With regards to knowledge, 60% of women of childbearing age knew the benefits of daily supplementation of folic acid. These women were more likely to have a high school or high level of education. Data will be further analyzed to reveal trends in folic acid use and knowledge with respect to age group, education level, race/ethnicity, marital status, and healthy lifestyle measures.

Conclusion: Folic acid use and knowledge among women of childbearing age in Florida are at encouraging levels. However, preliminary analysis shows that there are differences with respect to some demographic characteristics, such as education.

Public Health Implication: Findings from this investigation will aid the Florida Department of Health in identifying subpopulations that could benefit from more or variable education campaigns regarding folic acid supplementation and its benefit in preventing birth defects.

Folic Acid Use During Pregnancy and Child Behavior: Sino-U.S. NTD Prevention Project

Authors: *A.G. Ren, J. Bertrand, J.M. Liu, J. Gindler, R.J. Berry, H. Wang, A. Correa, L.Y. Wong, Y. Wang*

Background: Women of childbearing age are advised to increase their folic acid (FA) intake to prevent neural tube defects (NTDs) among their offspring. Whereas the beneficial effects of FA in preventing NTDs are well documented, few data exist regarding other effects of FA on fetal neurodevelopment.

Method: Following a program in China to prevent NTDs, the authors established prospective follow-up of children born to more than 247,000 study participants whose use of a pill containing 400 micrograms of FA before and during early pregnancy was well documented. A random sample of 9,123 singleton children aged 4 — 6 years was selected. The sample was stratified to achieve equal numbers by sex and maternal pill-taking status; 6 (0.07%) were excluded from the study because of invalid age. The Achenbach Child Behavior Checklist for children aged 4 — 18 years was administered to parents of 4,556 children of pill takers and 4,561 children of non-pill takers. Age- and sex-adjusted measures of 11 behaviors were categorized as "normal," "borderline," or "clinical" based on standardized norms.

Result: Among children of pill takers and non-pill takers, no differences in the rate of any reported behavior problems were observed. Immaturity, the least frequently reported behavioral problem, was reported for 1.9% of children of pill takers and 2.7% of children of non-pill takers (p=0.13); hyperactivity, the most frequently reported behavioral problem, was reported for 29.9% of children of pill takers and 29.1% of children of non pill takers (p=0.58)

Conclusion: In this population-based follow-up study, daily maternal consumption of FA before and during early pregnancy did not influence behavior in children aged 4 — 6 years.

Public Health Implication: This was the first first large, population-based evaluation of the long-term health effects of 400 micrograms of periconceptional FA use. FA is safe and does not affect children's behavior.

Framework For Diagnosis and Intervention For Children with Fetal Alcohol Syndrome and Their Families

Authors: *J. Bertrand and Interventions for Children with FAS/ARND Research Group.*

Background: To date, information about interventions appropriate for children with Fetal Alcohol Syndrome (FAS) or other alcohol related disorders and their families has been gleaned from other disabilities, informal networks, or trial & error. Although informative to a limited degree, such treatments have been implemented without being evaluated systematically or scientifically. In 2001, CDC provided the first federal funding to develop systematic, specific, and scientifically evaluated interventions appropriate for children with FAS and their families. This presentation will outline the framework developed by a consortium of five research sites across the country and CDC to develop diagnostic assessments and specific interventions for children with FAS and their families. In contrast to traditional interventions that target a single skill, interventions within this framework target skills in the child, provide parenting/family training, and provide ancillary services (eg, occupational) tied to a comprehensive evaluation of child. Interventions implemented within this framework aim to improve the developmental outcomes of individuals with FAS, reduce secondary conditions, and improve the lives of families affected by FAS.

Method: Children ranging in age from 3 to12 years participated across sites. The study sites include: University of California at Los Angeles; Marcus Institute, Atlanta, GA; Children's Research Triangle, Chicago, IL; University of Washington, Seattle, WA; and University of Oklahoma Health Sciences Center. A basic component of the framework was that each child received a comprehensive multi-disciplinary assessment that guided referrals and treatments (eg, speech therapy, special education). Following assessment, children are then randomized into treatment (N=50 per site) and control groups (N=50 per site). In addition to the standard of care, treatment groups received interventions focused on one of the core vulnerabilities associated with FAS, including: math skills, social communication, peer relations, foster care stability, compliance, and challenging behaviors. Control children continued with standard care in their community. All sites included a component of specific instruction and training for parents and caregivers as part of the intervention process. In addition to the intervention research portion of this project, preliminary information from a collaborative database of neurodevelopmental characteristics of children with FAS

was collected. These data were obtained from baseline and post intervention assessments administer at each site. Since many of the sites use the same standardized instruments, data were combined cross site. Sample sizes across domains of interest range between 200 and 500 children with FAS or alcohol related disorder; thus, providing the largest dataset to date on the profile of neurodevelopmental characteristics of children with FAS between the ages of 2 and 12 years. Domains of neurodevelopment assessed include: Executive functioning, attention, memory, social language, visual-motor integration, social functioning, and psychopathology.

Result: Preliminary findings indicate that the framework provides an effective means of intervention to children with FAS or other alcohol related disorders and their families. Post test measures at all study sites indicate a reduction in negative behaviors and an increase in positive behaviors/skills that improve the developmental outcomes, reduce the risk of secondary conditions, and improve the overall lives of families affected by FAS.

Conclusion: Challenges and obstacles to implementation of the overall framework and specific interventions will be discussed first. Effectiveness of the overall framework of comprehensive assessment, parental training, and specific skill building as assessed by group comparisons and pre- post- intervention analyses, also will be presented. Finally, descriptive data from the collaborative neurodevelopmental dataset will be included.

Public Health Implication: This program demonstrates the value of using primary interventions as a means to improve developmental outcomes, to prevent secondary conditions (including serious health concerns), and improve the lives of children with FAS or other alcohol related disorders and their families.

Gastroschisis In Utah: A Population-Based Study of BMI and Seasonality

Authors: *M. Feldkamp, J. Herrick, J. Carey*

Background: Gastroschisis, an abnormality of the ventral abdominal wall, usually occurs as an isolated defect most often to the right of the umbilicus. Gastroschisis sometimes occurs with amniotic band sequence or limb-body wall complex. The etiology of gastroschisis is unknown but a consistent and strong risk factor is young maternal age. The purpose of this case-control study is to investigate maternal age, BMI and seasonality of these defects in Utah identified through the Utah Birth Defect Network (UBDN) compared to live born controls. Additionally, prevalence of gastroschisis occurring with and without limb body wall defects will be presented.

Method: Data are derived from all gastroschisis cases occurring between 1997-2003 in the UBDN. Potential cases were reviewed by a pediatric dysmorphologist and classified as isolated, multiple, syndromic with an assessment of whether the case is familial (first degree relative with similar birth defect) and if etiology is known (teratogenic, genetic or chromosomal). Healthy controls were randomly selected from birth certificates during the same time period.

Result: A total of 158 cases were reported to the UBDN during this time period with 119 (75.3%) classified as isolated gastroschisis cases. The remaining 24.7% were classified as amniotic band sequence, limb-body wall complex, multiple or chromosomal. Overall prevalence was 0.48 per 1,000 births. However, excluding amniotic band sequence and limb body-wall cases with gastroschisis, prevalence was 0.42 per 1,000 births.

Conclusion: Frequency and prevalence for gastroschisis will vary based on case definition. Although the identification of gastroschisis in Utah has only occurred since 1997, there is no increasing trend with or without inclusion of amniotic band sequence and limb-body wall complex. In 2001, gastroschisis had the highest frequency.

Public Health Implication: Critical to any surveillance system is the ability to identify as close to 100% of cases to report appropriate prevalence and determine if public health measures impact the baseline prevalence. Case definition is important in order to better define risk factors. Gastroschisis that occurs with either amniotic band sequence or limb body wall complex is thought to occur by a different mechanism than isolated gastroschisis. This distinction should be clearly delineated in prevalence rates as well as epidemiologic investigations.

Genotyping of Single Nucleotide Polymorphism (SNPs) Associated With Deafness As An Adjunct To Physiological Screening For Congenital Hearing Loss

Authors: *K. White, R. Torres, D. Ward, J. Carey*

Background: Genetic mutations cause at least 50% of all childhood hearing loss, with connexin mutations alone accounting for at least 20% of all congenital hearing loss. There is also reasonably good evidence that congenital cytomegalovirus (CMV) accounts for at least 20% of all childhood hearing loss. Although the importance of detecting genetic mutations and/or the presence of congenital CMV has been recognized for years, there has not been a practical way to do it. Recent technological developments in SNP analysis have created the possibility of a fast, relatively inexpensive, and accurate procedure that can be used to detect genetic mutations and the presence of congenital CMV.

Method: The accuracy of SNP Analysis for detecting mutations associated with hearing loss was tested by evaluating DNA from 15 subjects, 8 of which had one of three connexin mutations and 7 of which had no mutations.

Result: In a blinded experiment, the SNP analysis technique successfully identified 14 of the 15 samples.

Conclusion: Although refinement is needed, it appears that SNP analysis could be used successfully as an adjunct to hospitil-based newborn hearing screening using physiological tests.

Public Health Implication: By combining physiological testing with SNP analysis, state-based EHDI programs and primary care physicians can better target follow-up efforts (including monitoring for late onset loss), costly medical procedures for young children identified with hearing loss can be avoided in many instances, medical care for newborns with some genetic mutations can be provided more efficiently, and parents could be given earlier and more accurate information about what caused their child's hearing loss.

Health Care Professionals Awareness and Practics Regarding Folic Acid

Authors: *S. Abelman, J. Petrini, K. Damus, C. Stone*

Background: The United States Public Health Service and Centers for Disease Control recommend that all women capable of becoming pregnant consume 400mcg of folic acid daily. This amount may help reduce the risk of having a neural tube defect-affected pregnancy. Research shows that women are not aware of the use of, or appropriate timing for, consumption of folic acid. The objective of these studies was to determine awareness of, and response to, the USPHS folic acid recommendation among a national sample of health care providers.

Method: A random sample telephone survey conducted in June/July 2002 among 361 OB/GYNs and 250 FPs. A random sample telephone survey conducted in June/July 2003 among 200 CNMs, 100 NPs, 55 Pas, and 144 RNs. All respondents provided direct patient care to women ages 18-45.

Result: One-half (50%) of providers knew that approximately one-half of all pregnancies are unplanned. Ninety percent of providers recognized folic acid supplementation should begin at least a month before conception and 86% reported always recommending folic acid to women planning pregnancies. However, providers reported seeing less than 25% of prenatal patients preconceptionally. Only 24% of providers always recommended folic acid to non–pregnant women, ranking very low on a list of issues at annual well-woman examinations. Awareness of folic acid's benefits regarding some birth defects was very high (97%), although just over one-half (51%) misstated the correct dose. Almost three-quarters (69%) misstated the correct dose for women with a previous NTD-affected pregnancy. Lack of information (40%) and lack of time during a busy exam schedule (30%) are cited as major factors that prevent health care professionals from addressing folic acid with their patients.

Conclusion: Knowledge about folic acid birth defect benefits was high among respondents, but more education about correct doses and percentage of unintended pregnancies is needed. Promotion of folic acid was greatest for women contemplating pregnancy; however, respondents reported that few women receive preconceptional care. Thus the need to continue and expand efforts to educate providers of health services to women of reproductive age about folic acid.

Public Health Implication: Folic acid use could increase and neural tube defects decrease if providers promoted the folic acid message to all women capable of having children at every available opportunity.

Health Inequalities in New Mexico: Policy Implications for Disability and Health Policy in Rural States

Authors: *A. Cahill, S. Gray*

Background: Chapter Six of Healthy People 2010 established for the first time as a goal the elimination of health disparities between people with and without disabilities in the U.S. population. What disparities exist, currently and what are the public health implications for policies and programs in a large, rural state such as New Mexico?

Method: The information in this paper is based on interviews conducted with nearly 11,000 New Mexicans through the Behavioral Risk Factor Surveillance Survey (BRFSS)between 1998 and 2001.

Result: Significant health inequalities exist between New Mexicans with and without disabilities. Disability increases with age and decreases with education and income. Those with disabilities are more likely to be overweight, have additional chronic health problems, access health care less often, and report a lower quality of life on multiple indicators.

Conclusion: It is clear that health inequalities exist between people with and without disabilities in New Mexico. National data from the BRFSS confirms that this is not limited to New Mexico or any other single state.

Public Health Implication: These findings have significant public health implications for policies, programs and services in New Mexico and other large, rural states. These include assessing the socioeconomic determinants of disability, increasing health promotion efforts, and inceasing efforts to develop better definitions of disability.

Health Literacy Issues for Families of Children with Disabilities and Complex Medical Needs

Author: *J. Moss*

Background: Parent of two Children with Developmental Disabilities Director Community Leadership, UCEDD of OK Core Faculty Oklahoma LEND Chair Family Supportive Health Care Network

Method: Combined literature review and survey of families in the Family Supportive Health Care Network regarding health literacy issues and accommodations for families, derived from families.

Result: Pending

Conclusion: Families frequently confuse medication and or health directives and do not understand basic health communication, they are unable to translate doctors orders into regimine.

Public Health Implication: Managing complex disabilities/medical issues effectively is dependent on health literacy of families. This means that translation of research, and alterations in practice and written and verbal directions from practitioners are needed. Accommodations suggested.

Health of Persons with Mobility Limitations

Authors: *E. Rasch, B. Altman*

Background: Recent national data indicate that approximately one of every five non-institutionalized adults reported some type of disability as defined by functional or activity limitations (Census 2000). This is significant since their health is, in aggregate, worse than that of the general population. Although secondary conditions have serious negative consequences for persons with disabilities, little is known about their epidemiology. Review of the scientific literature reveals gaps that seriously limit interpretation of findings, including lack of the following comprehensive inclusion of primary conditions causing disability and secondary conditions, nationally representative sampling comparison to reference groups, and clarity regarding the temporal order of conditions. This research will examine the health of community dwelling adults with mobility limitations in the U.S. relative to adults with other limitations and without limitations by characterizing pre-existing and incident health conditions that arise over a 2-year period.

Method: A secondary statistical analysis of data from the 1996-97 Medical Expenditure Panel Survey (MEPS) household component will be performed. Data on the non-institutionalized, civilian U.S. population were collected longitudinally through five rounds of interviews over a 2-year period. Self-reported health conditions were enumerated at each round of data collection and coded to 1996 ICD-9-CM codes. For this analysis, the sample was restricted to adults, 18 years of age and older (n=15,386). Based on self-reported limitations, respondents was categorized into mobility, other, and no limitation groups. Pre-existing conditions were identified in Round 1. Pre-existing and incident conditions were counted as distinct if they fell into separate AHRQ Clinical Classification System categories. Cumulative incidence of conditions with an

onset in Rounds 2-5 (not present in Round 1) were calculated. The number of pre-existing and incident conditions were tallied and compared across limitation groups using ANOVA ($p<0.05$). Frequency distributions will be used to rank order the most frequently occurring pre-existing and incident conditions across limitation groups. Sample weights and specialized statistical software (SUDAAN) were used to adjust for differential selection probability and generate variance estimates.

Result: Results will be forthcoming.

Conclusion: Conclusions will be forthcoming

Public Health Implication: The health of persons with disabilities is now a national priority. Recognition of the epidemiology of secondary conditions among persons with mobility and other limitations is a necessary first step toward development of effective public health interventions for this segment of the population.

Herbal Use in Pregnancy: Results from Two Studies

Authors: *C. Louik, M. Honein, M. Werler, S. Hernandez-Diaz, A. Mitchell*

Background: Herbal supplements have received a great deal of attention in the lay press as treatments for a variety of conditions, but little is know about their use during pregnancy.

Method: Data from two large case-control studies were used to describe prevalence and patterns of herbal supplement use among pregnant women. Both the National Birth Defects Prevention Study (NBDPS) and the Slone Epidemiology Center Birth Defects Study (BDS) are multi-site case-control surveillance programs in which mothers of both malformed (cases) and unaffected infants (controls) are interviewed about exposures immediately before and during pregnancy. Specific questions about herbal use were initiated in mid-2000 in the NBDPS and in 1998 in the BDS; herbals were defined as any product containing a plant, plant part, or plant extract.

Result: In the NBDPS 918 control mothers were interviewed after the specific herbal question was added, of whom 100 (10.9%) reported using some herbal. In the BDS, 10,219 women were interviewed, of whom 1609 (15.8%) reported such use. Both studies reflected considerable geographic variation in prevalence of use, with rates ranging from about 5% to over 16% in NBDPS and from 10% to 20% in the BDS. Both studies also found a relationship between herbal use and maternal age and education. In the BDS, there was also an association with increasing body mass index. Herbal use during pregnancy appears to be increasing over time. Prevalence of use according to month of pregnancy did not vary greatly, although the use of individual herbals did change throughout pregnancy. Commonly reported herbals in both studies included echinacea, ginger, herbal tea, and herbal-containing multivitamins, but no product was used by more than 1%.

Conclusion: Although overall use of herbals among pregnant women may be as high as 15%, the rates for individual products are quite low. Similarly, although the use of herbals overall may be increasing over time, the secular trends for individual products vary. A substantial proportion of herbal exposure occurs as a component in a multivitamin.

Public Health Implication: Future trends in the use of specific herbal products are unpredictable. Because much of the use is in multivitamins, it is unclear whether women are choosing to use herbals or are unwittingly exposed as manufacturers add herbals to their formulations.

Hospitalizations of Infants with Birth Defects In The United States Before and After Fortification of Grains With Folic Acid

Authors: *J. Robbins, J. Mick Tilford, T. M. Bird, M. Cleves, J. Alex Reading, J. Thompson, C. Hobbs*

Background: Rates of newborn hospitalizations for select birth defects have declined since mandatory fortification of grains with folic acid began. The cumulative impact of birth defects on hospitalizations of infants and children since fortification is not known. In this presentation, we analyze a unique hospital discharge database to determine whether rates of hospitalization and patient charges for hospitalizations of infants with birth defects thought to be influenced by folic acid have declined significantly following mandatory folic acid fortification.

Method: This paper is based on data from the Agency for Healthcare Research and Quality Kids' Inpatient Database (KID). The KID is the only national all-payer database of hospital discharges of children. Analyses compared rates of hospitalizations and hospital charges for select birth defects expected to be influenced by

folic acid and defects not known to be influenced by folic acid.

Result: Rates of hospitalization per 10,000 infants up to the age of 2 years decreased significantly from 1997 to 2000 for spina bifida (5.6 to 4.5), common truncus (.94 to .82), tetralogy of fallot (6.4 to 5.9), and lower limb reductions (.97 to .87). Rates of hospitalization for defects not thought to be influenced by folic acid (diaphragmatic hernia, esophageal atresia, and hypospadias) did not change or went up between 1997 and 2000. Total charges for hospital days of infants with spina bifida (expressed in 2000 dollars) was $112 million in 1997 and $100 million in 2000, representing an annual hospital charge savings of 11%.

Conclusion: Hospitalizations and hospital charges for birth defects known to be associated with folic acid have declined in the post fortification era. These results may be due to a more pervasive effect of fortification than previously thought or to changes in other birth defects risk factors, changes in criteria for hospital admission, or changes from inpatient to outpatient management.

Public Health Implication: Data on actual hospitalizations for neural tube defects have the potential to better inform the societal savings realized from fortification of grains with folic acid. Evidence that hospitalizations and hospital charges for other birth defects have also declined further supports the pervasive benefits of fortification.

How Many Children with Delays In Development Do Doctors Find?

Author: *M. Pavan*

Background: Early identification of children with genetic and developmental conditions is a challenge. Although some children are identified in the prenatal and neonatal periods due to dysmorphic features and complex medical conditions, the majority of children with developmental disabilities are identified only when delays in development become apparent. Unless a parent expresses concern about a specific problem, physicians only have the eleven recommended well child visits in the first three years to identify a child who may have delays in development. A physician is required to tell parents about the Part C Program of the Individuals with Disabilities Education Act so that families can access multidisciplinary evaluations, service coordination, and services to assist them. This review looks at how successful physicians are in finding children with delays in development and referring them to the Part C Program.

Method: One nurse (with intermittent support from two other nurses) provided intake for the Early Intervention Program for two counties in Florida over the last seven years (1997-2003). On intake, the nurse asked each parent who told him/her to call the Early Intervention Program and recorded the answer. The nurse compiled the data every six months to show the source of referrals. The data are grouped in eight broad groups: physicians, therapists and audiologists, community screening and transition agencies, other community agencies, families, day care systems, other Early Intervention Programs, and community based home visiting programs. The number of referrals from each group was analyzed using an Excel spreadsheet.

Result: Data show a steady increase in the total number of referrals by 8% per year from 599 to 931. The two largest referral sources were physicians at 24 + 3%, and therapists and audiologists at 21+ 4 %. Referral rates for the other groups were: community screening and transition agencies, 17 + 2%; families, 10 + 2%; day care systems, 6 + 4%; other Early Intervention Programs, 5 + 1%; and community based home visiting programs, 4 + 2%. Referrals from day care systems showed significant increase from 1 to 14%.

Conclusion: Physicians are part of the community identifying children with delays. Most of the referrals come from other professionals and agencies working with children and their families. This study may underestimate physician referrals for several reasons: 1) physicians may refer to therapists and audiologists in a medical model rather than the Part C Program, 2) families may request the medical model, at least initially, and 3) physicians may refer to screening programs as an initial step when delays are suspected. In February 2001, and March 2003, mailings about the importance of early identification and referral were sent to physicians. Although this may have maintained referrals, no specific effect on physician referral rate is noted.

Public Health Implication: Physician involvement in developmental pediatrics is essential. This may be in identifying and referring children with delays, or in collaborating with others involved in the child find process. Even when the physician does not refer a child to the Part C Program, families and specialized teachers need to share information with the physician about the services and keep the physician involved for

long term care. New ways to assist primary physicians with this challenging task are needed.

Hypospadias and Maternal Intake of Progestins and Oral Contraceptives

Authors: *S. Carmichael, G. Shaw, C. Laurent, M. Croughan, R. Olney, E. Lammer*

Background: Maternal intake of progestins and oral contraceptives may impact hypospadias risk by interfering with the production or action of fetal androgens, which are critical to normal urethral closure. This study examines the association of these exposures with hypospadias risk among offspring.

Method: This study uses data from the National Birth Defects Prevention Study, a multi-state, population-based case-control study including data on severe hypospadias (i.e., the urethra opened onto the penile shaft, scrotum or perineum) in babies delivered from 1997-2000. Non-malformed, liveborn controls were selected randomly from birth certificates or birth hospitals. Maternal interviews were completed by phone, within 24 months after delivery, with 449 case and 1255 control mothers.

Result: Intake of progestins to help the mother become pregnant or prevent pregnancy loss was associated with increased hypospadias risk. The odds ratio (OR) was 5.0 (95% confidence interval (CI) 2.5-10.0) during the month before pregnancy, 3.7 (95% CI 2.1-6.4) for any intake during month 1 of pregnancy, and 3.1 (1.8-5.3) during month 2. The OR for intake of oral contraceptives was 0.8 (95% CI 0.5-1.2) during the month before pregnancy and 0.6 (0.3-1.2) during month 1 of pregnancy.

Conclusion: Bivariate results suggest that maternal intake of progestins may be associated with increased hypospadias risk.

Public Health Implication: Potential alternative explanations (e.g., assisted reproductive technologies, subfertility, recall bias) must be explored to improve our understanding of this preliminary finding.

Identifying Young Children At Risk For Developmental Delays

Authors: *M. French, S. Frehywot*

Background: More children may be at risk for developmental delays, and methods exist to identify such children in the early years. A growing body of evidence indicates that early diagnosis and intervention for developmental delays, including ASD, are efficacious in improving long-term outcomes. However, many developmental disorders are diagnosed when children start school by which time the potential for treatment to improve outcomes may be lessened.

Method: Our objectives are to 1) examine current policies of three stakeholders — health plans, employer-purchasers, and childcare programs — regarding early screening for developmental delays among young children; and 2) identify strategies to increase these stakeholders' support for identifying young children at risk for developmental delays. This study includes the following: a) synthesized peer-reviewed literature and secondary sources, used to summarize barriers and opportunities to identifying children at risk for developmental delays in clinical and childcare settings; b) conducted stakeholder interviews in order to understand current policy for identifying at-risk children; examine gaps in policy and practice and their origins; and develop strategies to assure at-risk children are identified; c) an examine of potential policy approaches in stakeholder roundtables to refine strategies and prioritize future research.

Result: Promising tools exist for identifying at-risk young children, but often are not used in clinical and childcare settings. Common barriers include insufficient time, training, resources/reimbursement, consumer demand, and professional consensus on best practices. Most commercial health plans bundle risk identification for developmental delays into well-child visits and may provide case-by-case reimbursement for screening as needed. Gaps exist between federal policy and delivery of screening for developmental delays to Medicaid-enrolled children. Many employers are unaware of the potential to identify at-risk children in clinical and childcare settings.

Public Health Implication: Opportunities currently exist to routinely identify young children who are at risk for developmental delays. Widespread adoption of such practices, however, may require further advances in evidence-based medicine, practice tools and models, and networks of developmental services. Health plans can sponsor continuing medical education in child development, provide pediatric practitioners with feedback on the delivery of developmental services, explicitly add developmental screening as a benefit, and participate in coalitions to create a seamless network of community resources for early childhood

development. The effectiveness of existing methods for identifying potential developmental delays in clinical and childcare settings should be established. Researchers also should develop quality improvement measures relating to identifying at-risk young children.

Impact of Prenatal and Newborn Screening on Diagnostic Trends in Cystic Fibrosis: United States, 1996-2002

Authors: *S. Lyn, S. Grosse, L. Bradley, B. Marshall, M. Gwinn*

Background: Cystic fibrosis (CF) is the most common autosomal recessive, lethal disease in America. Since 1966, the Cystic Fibrosis Patient Registry (CFPR) has collected annual medical information about American CF patients to guide secondary prevention efforts. The CF gene, CFTR (cystic fibrosis transmembrane regulator), was identified in 1989, and pilot studies of prenatal and newborn screening for CF have been conducted. In 2001, both the American College of Obstetricians and Gynecologists and the American College of Medical Genetics recommended that CF carrier testing be offered to all women and couples who are planning a pregnancy or are pregnant. Eight states include CF among routine newborn screening tests and other states are considering doing so.

Method: Prenatal and newborn CF screening methods and policies from 1987 to 2002 were reviewed. We analyzed information about patients registered by the CFPR from 1996 to 2002, including age at CF diagnosis and whether prenatal testing or newborn screening was used.

Result: Preliminary: From 1996-2001, the median age of CF diagnosis remained between 6 and 7 months. In each year, 2-4% of CF patients were identified by prenatal screening. The proportion identified by newborn screening increased during this period, from 5% in 1996 to 9% in 2001 (p=0.003). Clinical symptoms of CF led to confirmatory testing in most patients.

Conclusion: Newborn screening for CF is increasing in the United States. Prenatal CF carrier testing is likely to increase following new recommendations from the American College of Obstetricians and Gynecologists and the American College of Medical Genetics.

Public Health Implication: Earlier identification of CF patients by prenatal diagnosis and newborn screening has the potential to change the characteristics of the CF population. It may also have important implications for secondary prevention. The CFPR has a key role in monitoring the effects of these changing screening practices.

Improved Sleep Quality And Daytime Function In 3 Adults with ADHD As A Result of Bilateral Morton's Neuroma Injections

Authors: *L. Lettau, C. Gudas, B. West*

Background: Sleep difficulties are common in adults/children with ADHD, and improved sleep quality, such as achieved through correction of obstructive sleep apnea by tonsillectomy, improves ADHD symptoms. Restless legs syndrome (RLS) and associated sleep-disrupting nocturnal leg movements (NLM) occur frequently in adults/children with ADHD as well as in their parents. Ongoing, unpublished research by our group has found that Morton's neuroma, a focal entrapment neuropathy in the ball of the foot, is a common and treatable cause of RLS-NLM.

Method: Two physicians (37 y/o male, 26 y/o female) and a teenager (17 y/o male), each with ADHD, RLS and/or NLM, and physical signs of foot neuromas, were treated with a series of bilateral neuroma injections using a mixture of steroid/anesthetic/absolute alcohol. Leg restlessness (LR), poor sleep quality (PSQ), and daytime fatigue (DF) were assessed by serial 10cm visual analogue scales (VAS). Changes in ADHD-related symptoms post-neuroma treatment were assessed with serial Connors Adult ADHD Rating Scales (CAARS) using both self and observer reported long forms.

Result: Sustained mean (range) % improvements in VAS scores were: LR - 72% (52-92%), PSQ - 93% (86-100%), DF - 82% (66-92%). Serial CAARS forms showed decreased T scores in 11/12 self ratings and 12/12 observer ratings over the 4 categories of inattention/hyperactivity/ADHD index/total symptoms. Six of the 23 T scores that improved were reductions of >10 indicating >1 standard deviation.

Conclusion: This small case series indicates that effective treatment of RLS-NLM by bilateral neuroma injections, can substantially improve sleep quality and thereby lessen ADHD-related symptoms.

Public Health Implication: These results support further investigation into the role of neuroma-related chronic sleep disruption/deprivation in the pathogenesis, clinical manifestations, and treatment of ADHD.

Improving Child Find: Process and Products from Five States

Authors: *B. Shapiro, M. Bruder, D. Nelson, T. Maloney, A. Capone, C. Robinson*

Background: Child Find is the system to identify children with or at risk for disabilities, and refer them to early intervention or special education services. All states are federally mandated to conduct Child Find programs. However, national and state data suggest that states are not enrolling expected numbers of children in these services.

Method: Each state project performed a needs assessment, developed strategies or new activities to address gaps and barriers, demonstrated and evaluated the strategies/activities. Projects targeted physician referral, newborn hearing screening, child welfare services, or local community outreach.

Result: Five states have demonstrated diverse ways to improve Child Find ranging from improving the Newborn Hearing Screening system to improving Child Find in rural communities to a statewide systems improvement model. Evaluation strategies and findings vary across the five states but some models report robust support.

Conclusion: The effectiveness of state Child Find programs can be increased at many different levels depending on state characteristics and priorities.
Public Health Implication: Systematic planning, implementation and evaluation of Child Find improvement strategies can increase access to early intervention/special education services.

Improving Preconceptional Folic Acid Intake Among College-Aged Women

Authors: *H. Krowchuk, R. Lester, S. Verbiest*

Background: About 70% of all neural tube defects (NTDs) can be prevented if all women of childbearing age take 0.4mg folic acid daily. However, most women of childbearing age do not take daily folic acid, and their diets are not folate-rich. Women ages 18-24 are least likely to consume a vitamin containing folic acid, and about 59-78% pregnancies in women 18-24 yrs. are unintended. Objectives of this study were to assess: 1) knowledge about the role of folic acid in preventing NTDs; 2) frequency of intake of 0.4mg folic acid; and 3) effectiveness of peer education in improving folic acid consumption among women ages 18-24 years, attending college at one of 40 campuses in North Carolina from 2000-2003.

Method: Folic acid knowledge pretests (20 item questionnaire, reliability = .89) were administered to 3,890 volunteer participants (mean age: 20.2 + 1.8 yrs.). Two health educators and 22 students trained as folic acid peer educators provided educational sessions to participants in small groups. A 100-day supply of a multivitamin containing 0.4mg folic acid were provided to participants after completion of a session, and post-tests to determine folic acid use (self-report, verified by vitamin count) and knowledge (22 item questionnaire, reliability = .87) were administered randomly to 40% of the participants at 1 month and 1 year after session participation.

Result: At enrollment, 55% had heard of folic acid, 45% knew NTDs could be prevented with multivitamins, and 32% knew preconceptional vitamin use was necessary. Only 30% reported taking daily folic acid supplementation prior to their participation in the educational session. Post-test scores demonstrated a significant increase in women's knowledge about folic acid; 82% reported daily folic acid consumption (verified by vitamin count) at 1-month follow-up. Forty percent of participants were contacted for 1-year follow-up, 68% reported daily folic acid consumption, and knowledge scores remained improved.

Conclusion: Focused folic acid peer education was effective in improving folic acid knowledge among participating students. Providing an initial supply of multivitamins also increased their use among college-aged women, and the behavior change (daily multivitamin use) was sustained in a small subgroup of the sample.

Public Health Implication: The combined strategy of education and multivitamin distribution may facilitate a continuation of daily adherence to multivitamin consumption, thus facilitating the prevention of NTDs.

In Their Own Words: The Uses of Personal Stories to Assess Program Impact

Author: *K. Wilson*

Background: Personal stories have been shown to be a powerful tool in social science research, health communication campaigns, and the legislative process. The use of personal stories in public health is an

important way to reach broad audiences and reflects CDC's effort to ensure that scientific knowledge is accessible and meaningful to the public.

Method: Personal stories from participants, families, providers, and principal investigators involved in programs supported by the National Center ion Birth Defects and Developmental Disabilities (NCBDDD) were collected through open-ended in-person or phone interviews. Interviewees provided personal stories about autism, hearing loss, folic acid use, child development, heart defects, living with physical disability, and fetal alcohol syndrome (FAS). The interview assessed the impact of a program on individual knowledge and resources to address their own condition or that of a family member or client, as well as perceived impact of the program on improving the health and resources available to the larger community to address that condition.

Result: Qualitative review of the interviews indicates customer willingness to provide personal testimony about their experiences in the program and speak positively about program's impact on their lives. Findings also suggest provider and principal investigator eagerness to use personal stories to inform legislative and other audiences about program accomplishments.

Conclusion: Personal stories provide a useful tool for assessing the impact of public health programs in that they complement more traditionally quantitative program summaries, progress reports, and performance evaluations.

Public Health Implication: Personal stories offer policy makers information that increases their understanding of program innovations and public health impacts, and help them visualize the program in action. In addition, this approach will help raise the visibility of NCBDDD's new and existing programs with policymakers and the public.

Increased Injury Risk Among People with Disabilities

Authors: *H. Xiang, M. Leff, L. Stallones*

Background: Injury has been studied extensively as a primary cause of disabilities. However, there has been little emphasis on addressing injury as a secondary condition in people who already have disabilities.

Method: A large population-based survey was conducted among non-institutionalized adults aged 18 years or over from January 1999 through October 2000 using the conceptual framework established by the International Classification of Functioning, Disability, and Health (ICF). Injury types, distributions, and risk factors were compared between people with disabilities and those without disabilities. Logistic regression analyses for survey data were used to study the relationship between disability status and injury risk controlling for confounding effects of demographic characteristics and complicated study design.

Result: Of the 2,692 adults who were interviewed successfully, a total of 21.8% of them reported to have disabilities – 5.2% reported severe disabilities and 16.6% reported moderate disabilities. People with disabilities were significantly more likely to sustain an injury in the previous 12 months. After controlling for the confounding effects of major demographic variables, the odds of incurring an injury in the last 12 months was 4.10 times higher for the respondents with severe disability (OR= 4.10; 95%CI=2.45-6.87) and 2.08 times higher for the respondents with moderate disability (OR=2.08; 95% CI=1.47-2.94) than the respondents without disability. More than half of the injuries (52%) among respondents with severe disability and 39.2% among respondents with moderate disability took place in the home. The most common causes of injuries among respondents with disability, severe or moderate, were being struck or hit from a fall.

Conclusion: People with disability are at an increased risk for injuries. There is a critical need to study injury as a secondary condition among people with disabilities and incorporate injury control and prevention into health promotion for this vulnerable population.

Public Health Implication: Injury risk among people with disabilities is an important health issue.

Increasing Access To Preventive Services For Women With Disabilities: The Accessible Tables Project

Authors: *L. Steele, F. Stevens, T. Paeglow*

Background: In a pilot project to promote access to cancer screening, diagnosis, and treatment services for women with mobility limitations, the DHP collaborated with the NYSDOH Cancer Services Program (CSP) to secure CDC funds for the purchase of 21 adaptive examination tables. Tables were placed with eligible

providers in the CSP's Healthy Women Partnerships. Eligibility criteria were: 1) documentation of wheelchair accessibility; 2) agreement for staff training in disability sensitivity and awareness; 3) agreement to collect data on all women served; and 4) willingness to conduct promotional outreach.

Method: Five regional training sessions were conducted spring 2002; tables were placed June 2002.
From April 2002 to June 2003, data were collected to evaluate the effectiveness of table placement in increasing clinic visits for cancer screening services by women with disabilities. For analysis purposes, the 15-month period was divided into three intervals based on intervention status: 1) Pre-Intervention (April-June 2002); 2) Intervention (July 2002-March 2003); and 3) Intervention/Comparison (April-June 2003). Primary comparisons were between the Pre-Intervention interval and the comparable 3-month interval the following calendar year (Intervention/Comparison interval). A self-administered anonymous questionnaire collected information on reason for visit, use of special equipment to get around, activity limitation status, and degree of limitation (need for assistance with personal care and/or routine needs).

Result: The percentage of total visits made by women with a greater degree of disability, i.e., those who reported an activity limitation that required assistance, increased from 6.0% during the Pre-Intervention interval to 8.3% during the Intervention/Comparison interval. The percentage of visits that were by women who were wheelchair users doubled from pre-intervention to comparison (1.0% to 2.0%). Moreover, the percentage of visits by women reporting the use of any type of assistive equipment increased from 7.9% to 10.6%. The percentage of total visits for breast examinations by women with a greater degree of disability increased substantially from pre-intervention to comparison (4.1% to 15.9%).

Conclusion: Initial results suggest a positive effect of the availability of accessible examination tables on enrollment of women with significant disabilities in cancer screening services, especially mammography.

Public Health Implication: The availability of adaptable examination tables has the potential to increase the use of preventive cancer screening services by the population of women with disabilities.

Integration of Newborn Screening With Other Maternal and Child Health Systems: A Sourcebook and A Tool For Assessment and Planning

Author: *D. Linzer*

Background: Newborn dried blood spot screening (NBS) is a public health activity that has been conducted for the past three decades and is universally accepted because of its profound impact on the health of newborns. It takes place within the context of State administered NBS systems and is comprised of: screening, short-term follow-up, diagnosis, management/ treatment, and evaluation. Education and quality assurance are integral to all components of the NBS system. The Newborn Screening Task Force issued a report in August 2000 supporting the integration of NBS information recommending that HRSA "facilitate and foster the involvement of NBS systems in infrastructure development activities in States."

Method: In response to this report, HRSA partnered with the Public Health Informatics Institute to identify and describe best practices among State Planning Grants, a qualitative assessment of seven newborn dried blood spot screening programs and their planning efforts to integrate.

Result: Two products were developed: 1) Integration of Newborn Screening and Genetic Service Systems with Other Maternal & Child Health Systems A Sourcebook for Planning and Development which describes nine key elements and what are considered best practices in their implementation as demonstrated by five State Planning Grantees with over-arching conclusions. 2) A companion to the Sourcebook, the Tool for Assessment & Planning assists public health teams in designing their child health information systems integration projects from planning through early implementation.

Conclusion: Use of these companion documents as building blocks will assist public health teams in designing their integrated child health information system thereby increasing the likelihood of success.

Public Health Implication: It is expected that improved coordination and integration of public health programs and their information systems will help to ensure an optimal healthy start for all children and improve the health of children by facilitating assessment and the prompt provision of services.

Investigating Developmental Delays Study: Comparison of SCQ and PDDST

Authors: *L. Lee, A. David, N. Lee, C. Newschaffer*

Background: To compare the effectiveness of the Social Communication Questionnaire (SCQ) and the Pervasive Developmental Disorders Screening Test (PDDST) in identifying autism spectrum disorder (ASD) among children age 3-5 years receiving special education services.

Method: A brief, self-administered questionnaire consisting of demographic questions and the SCQ and PDDST was mailed to all parents of children age 3-5 years receiving special education services through the Howard County School Districts, Maryland and a subset of willing participants in Christina School Districts, Delaware. Parent's report of the child's autism special education classification and/or an autism diagnosis was used to determine case status.

Result: Among 280 who returned completed surveys, 17.9% of these (n=50) were positive on either the SCQ (score >15) or PDDST (score >13). When compared to parents' report of ASD, the sensitivity and specificity of the SCQ was 56.6% and 92.1%, respectively, with a positive predictive value (PPV) of 62.5% and a negative predictive value (NPV) of 90.1%. The sensitivity and specificity of the PDDST were 15.1% and 98.7%, respectively (PPV 72.7% and NPV 83.3%). Findings from Receiver Operating Characteristic (ROC) curve indicated that score 11 was an optimal cut-off for SCQ (area under ROC curve=0.89), and score 7 for PDDST (area under ROC curve=0.85). ROC cut-offs yield sensitivity and specificity of 81.1% and 80.6% for SCQ and 81.1% and 78.9% for PDDST.

Conclusion: The use of conventional cut-off for SCQ and PDDST generates limited sensitivity for these two brief screening tools; while specificity is high, PPV is still fairly low even in this target population with enriched autism prevalence. Lowering the cut-off scores can greatly improve sensitivity. Future analyses will be conducted based on ADOS and ADI-R assessments being done in a subset of these children.

Public Health Implication: Given reports of rising ASD prevalence and the accepted effectiveness of early, intense educational interventions, early detection of ASD is of substantive public health import. The performance characteristics of proposed ASD screening approaches need to be assessed in population-based samples before specific strategies are recommended.

Investigating Linkage of Autism Spectrum Disorder Surveillance Data To Hazardous Air Pollutant Data

Authors: *G. Windham, R. Gunier, L. Zhang, L. Croen, J. Grether*

Background: The prevalence of autism appears to be increasing dramatically, but the causes remain largely unknown, raising concern that environmental factors may play a role. Substances that are known or suspected to affect neurodevelopment may be important, as well as those that interfere with the endocrine system during fetal development. We will explore the feasibility of using data compiled by the USEPA on hazardous air pollutants (HAPs) to investigate possible associations between autism and prenatal exposures through linkage to our autism surveillance system data.

Method: As part of the CADDRE network, we are conducting multi-source surveillance of autism spectrum disorders (ASD) among children born in 1994 in six counties of the San Francisco Bay Area. For this project we include initial cases ascertained from the state Department of Developmental Services and the Kaiser Permanente Medical Care Program. Liveborn controls are selected from linked birth-infant death vital records, frequency matched to cases by gender and month of birth, in a 2:1 ratio. Address at birth, as recorded on the birth certificate, is geo-coded to obtain census tract for linkage. The USEPA has estimated outdoor air concentrations of various HAPs by census tract nationwide, based on modeling emission inventory and meteorological data. We used the 1996 database that is closest to 1994, which includes 33 pollutants.

Result: We ascertained about 330 ASD cases and selected appropriate controls, so about 1000 births are included. The cases were predominantly male (82%), as expected. By race, the sample includes 63% Whites, with cases slightly more likely to be Asian or Black than controls. Parents of cases were less likely to be young or to have only a high school education than control parents. We identified HAPs with known or suspected neurotoxicity or developmental toxicity, and assessed whether there was variation in concentration across the 1228 census tracts in the region. This yielded 16 compounds, including heavy metals, volatile organic compounds, and PAH's. We examined categorical levels of the pollutants, individually and grouped by type, by selected demographic factors and case-control status.

Conclusion: This study efficiently addresses an issue of great concern, namely investigating the potential

environmental risk factors associated with autism, using methodology recommended in environmental health tracking programs.

Iodine Deficiency: A Major Preventable Cause of Birth Defects

Author: *J. Dunn*

Background: Iodine deficiency causes pregnancy complications, increased child mortality, mental retardation, hearing impairment, and other developmental disorders. This report will review its effects, means for its prevention, and current world status.

Method: Review of published studies and experiences.

Result: Currently about half the world's population lives in countries with significant iodine deficiency, risking its consequences. Data from school age children, the usual survey group, may not accurately reflect iodine nutrition elsewhere in the community, especially in its pregnant women. Iodized salt is the best known, but not the only corrective means. Mean community intelligence and other features improve on achieving iodine sufficiency. National programs vary widely in their success. Major issues are monitoring, advocacy, and sustainability.

Conclusion: Great progress has been made towards eliminating iodine deficiency as a problem of public health, but much more needs to be done.

Public Health Implication: Correcting iodine deficiency should be a priority for all countries, because it is straightforward, inexpensive, and highly effective. In the USA possible iodine deficiency in pregnancy needs careful attention.

Knowledge and Concern About Respiratory Illness In Males with Duchenne Muscular Dystrophy and Their Parents

Authors: *C. Trout, K. Mathews, J. Williams*

Background: Duchenne muscular dystrophy affects males and results in severe respiratory insufficiency in late adolescence or young adulthood. The patients and families have to make difficult decisions about life-prolonging aggressive treatment. There is limited systematically collected knowledge about how adolescents with DMD feel about the progression to possible death, the treatment options for respiratory insufficiency, and how health care providers should address these issues with them. The purpose of this study was to describe concerns of teenage males with DMD and their parents regarding end of life respiratory illness and treatment options.

Method: This study employed a two-group pretest-posttest design to evaluate understanding of respiratory illness and treatment options in the later stages of DMD before and after patient education. In addition, questionnaires were administered to assess level of concern about a variety of medical and psychosocial issues.

Result: Adolescents and parents demonstrated the ability to consider their complex medical situation and had a basic understanding of the breathing problems associated with DMD and treatment interventions. Scores on a multiple choice test improved following patient education, with parents and boys reporting better understanding of treatment options. Respiratory complications and assistance with breathing problems are significant concerns of DMD families. Families appreciated having frank informative discussions of these difficult issues.

Conclusion: Doctors and nurses involved in the care of these families should address the issue of respiratory insufficiency and educate families about treatment options. Anticipatory guidance is critical for families to make informed decisions about their healthcare and advanced directives. Successful interventions are often dependent on the availability of a variety of community support services, including knowledgeable healthcare providers, respite, hospice, and home care services. These services are not always available or utilized by all families.

Public Health Implication: Utilizing the families identified by MD STARnet, a Needs Assessment for Families of Children with Muscular Dystrophy begins in the spring of 2004. This study will 1) identify and prioritize the needs of patients and families with DMD and childhood-onset BMD at different times in the disease process, 2) identify factors that influence the availability of services and resources to families, and 3) determine how the diagnosis of DMD and childhood onset BMD impacts the patient and their immediate family members.

LIFE LONG HAPPINESS: A Preconception Health Education Project - Helping Women Make Healthy Choices

Authors: *J. Higgins, M. Gallaher, S. Newbill.*

Background: The goal of "Life Long Happiness: A Preconception Health Education Project" is to reduce the risk of birth defects through: increased awareness of the importance of folic acid intake, avoidance of tobacco, avoidance of alcohol and drugs, diagnosis and treatment of diabetes, and prevention of obesity through nutrition and exercise. The title "Life Long Happiness" is a concept of wellness arising from the Navajo culture, "Sa'ah Naaghai Bik'eh Hozhoon". A teaching module was developed in 2002. The module is a tabletop ring binder with laminated pages standing 2 feet tall by 19 inches wide. Illustrations for each of the topic areas are presented to the clients with a script facing the presenter to assist in the facilitation of a dialog with the client.

Method: This pilot project was designed to test the effectiveness of the module. Women between the ages of 14-44 years from 3 high-risk counties in NM were targeted to participate in learning interventions using the module. A pre test (S1) was administered prior to intervention and an identical post-test (S2) administered immediately following the intervention to ascertain gains in knowledge and several change variables. Three levels of information for each topic area could be presented depending on time available for the intervention: basic, preventative, extra. Levels of presentation were tracked to allow for comparisons amongst presentation formats. A follow up post-test (S3) was administered after a period of at least 8 weeks to elicit actual changes in behavior undertaken by the client, in each of the 5 risk areas, motivated by the intervention.

Result: A total of 400 women completed both S1 and S2, and 209 of them completed S3. Results of analysis of S1 and S2 show gains in knowledge and all change variables (importance to change, confidence to make a change and contemplation of change) with the application of the module. Analysis indicates that all gains increase with an increase in time spent in the intervention and increased level of presentation. Analysis of S3 indicates a loss in the (importance to change) variable over time. However, many women did report making a change in behavior and were at the "action" stage of change.

Conclusion: The module has been shown to be an effective teaching tool under a wide variety of presentations. Increased exposure to the advanced levels of information made a significant difference in increasing the client's awareness of the need to change behaviors, and increasing their confidence to make changes.

Public Health Implication: The success of the module at test Women, Infant, Child (WIC) clinics was critical in the program decision to adopt the module into the core curriculum for 63 statewide WIC clinics.

Linking Birth Certificate and Newborn Screening Data: Approaches, Results, and Lessons

Author: *S. Spence*

Background: Data linkage is increasingly important in coordinating and improving newborn screening surveillance, follow-up, and health profile development. Linking databases for surveillance requires accuracy and efficiency. Linking them for service assurance carries a higher standard of quality assurance, as well as greater emphasis on protection of families' right to privacy.

Method: The Office of Family Health in the Oregon Department of Human Services has developed an approach to combining newborn birth certificate, dried blood spot (DBS) screening, and hearing screening data for real-time follow-up, care coordination, and population surveillance. We use the DBS identification number on the birth and hearing screening records, backed up with a probabilistic matching of birth date, birthing hospital, newborn gender, mother's name, and newborn's last name. This three-way linking is done in stages, with repeated passes through the database, but no relaxation of matching criteria. The linked data populate a surveillance database for statistical analysis and reporting and will populate an interactive, point-of-service FamilyNet data system module when it is completed.

Result: A two-year pilot test demonstrated that this phased approach to data linkage is both successful and quick. The data matching approach consistently yielded about 96% true positive matches, no false positives, and few matches that required investigation (clerical review). After clerical review, the proportion of newborn records matched was more than 98% and the newborn records accounted for was 100%. The matched data populate a SAS analysis database; infant records can be updated based on changes in underlying hearing screening, DBS, and birth certificate records; and the

data are used in a temporary front-end application (pending completion of the FamilyNet module).

Conclusion: The use of newborn hearing, DBS, and birth certificate data in the matching produces a rich database for analysis of sequelae of pregnancy and childbirth, including genetic conditions. The success of the data matching approach demonstrates the advantages of combining deterministic and probabilistic strategies and the value of not relaxing matching criteria. The use of statistical analysis software as "middleware" allows automation of file management and update of matched data based on changes to the underlying data. The SAS files also permit epidemiological analysis and reporting for surveillance. The link to an interactive data system will continue to assure accuracy of match and allow timely, confidential follow-up.

Public Health Implication: Rapid, accurate data linkage makes public health program data more useful to families and providers, improving the likelihood of timely, appropriate service. Linked data allows comparative analyses that can validate our assumptions about the measures we use to guide program decision. Linked data form a rich base for population surveillance. Data linkage adds value as long as we understand the quality of our linkages and the parameters for appropriate data use.

Linking Birth Defects (BD) Surveillance With Prevention and Early Intervention (EI)

Authors: *W. Wertelecki, T. Miller, S. Shivers, B. Prince, A. Widgeon, P. Hilliard, and B. Oliver*

Background: The Alabama Birth Defects Surveillance (ABDS) has longstanding linkages with state programs concerned with public health, mental health/mental retardation, early intervention and rehabilitation services. Regarding "Medical Homes" (MH), studies show that patients listen and act upon recommendations by their health care providers who, however, often fail to promote folic acid (FA) supplement use by their patients. We report our attempt to involve MH in BD prevention roles.

Method: A letter to all Alabama physicians (~ 7,000) urged them to recommend folic acid supplements, including higher doses to those women at risk of NTD recurrence. In addition, 1,800 physicians most likely to provide services to families at risk of NTD recurrence were encouraged to participate and identify an "Office Champion" (OC) to represent their MH. The ADPH provides women at risk for NTD with free 4 mg. folic acid through their participating MH. The ABDSPP provides FA educational materials, patient access to genetic counseling, and training programs for health-care professionals. To further strengthen our partnership with MH, a quarterly BD prevention newsletter was designed. The ABDSPP contacts MH upon detection of infants with BD who might benefit from EI as another strategy to link MH with BD prevention. The notification to MH includes context specific fact sheets for health care providers as well as information for families. Follow-up contacts with MH are in place. To facilitate the above, a web-based BD information system (IBIS) was developed. IBIS provides access to selected fact sheets for health care providers as well as families, including parental support organizations.

Result: Thus far, the impact on the prevention of NTD is moderate and on recurrence is modest. However, regarding BD in general, interactions between MH, BD surveillance and state programs are steadily growing as a functional partnership.

Conclusion: Interactions of BD surveillance with MH, EI, and state agencies are an effective process to promote BD prevention in general.

Public Health Implication: Establishing a mandated NTD reporting system linked with an intervention protocol is feasible and likely to be most effective given an existing partnership with MH.

Livebirths with Neural Tube Defects: Combined Impact of Prenatal Diagnosis and Folic Acid Utilization

Authors: *R. Stevenson, L. Seaver*

Background: The objective of the study was to determine the relative contribution of prenatal diagnosis/pregnancy termination and folic acid utilization or other unknown factors to the reduction of neural tube defects (NTD) cases in South Carolina (SC), a region of high NTD risk.

Method: Active and passive surveillance methods were used to identify all pregnancies/infants with NTDs in SC during the ten-year period from 1992-2002. The number of NTD cases that resulted in 1) spontaneous abortion or fetal death, 2) induced pregnancy termination, and 3) livebirth were determined. The expected number of NTD affected pregnancies for the ten-year period was calculated based on the 1992 rate.

NTD cases expected to be lost to spontaneous abortion/ fetal death, NTD cases terminated after prenatal diagnosis, and known livebirths were subtracted from the expected number of NTDs to determine the number of cases that would have occurred without increased folic acid utilization or other unknown factors.

Result: Based on the 1992 prevalence rate, 968 NTD-affected pregnancies would have been expected in SC over the ten-year period. The projected number of NTD cases lost to spontaneous abortion or fetal death during this period was 118 (69 observed, 69 postulated) and 267 known cases of prenatally diagnosed NTDs were terminated. While there should have been 583 livebirths with NTDs, only 228 occurred during this time period, which is a potential reduction of 335 NTD cases due to folic acid utilization or other unknown factors.

Conclusion: On the basis of the occurrence figures in SC, the larger share of the reduction of NTD cases (355 cases, 57%), may be plausibly attributed to greater access to folic acid and unknown factors which contribute to lowering the risk of NTDs; the lesser share (267 cases, 43%) was due to prenatal diagnosis and pregnancy termination.

Public Health Implication: The number of livebirths with neural tube defects has signficantly decreased due to primary prevention with increased intake of folic acid through dietary fortification and supplementation, and perhaps other yet unknown factors.

Living with Multiple Sclerosis In The United States and Germany: Consumers' Experiences with Health Care Services

Authors: *T. Kroll, J. Klewer, P. Beatty, J. Kugler*

Background: Multiple sclerosis (MS) is a debilitating neurological condition that affects approximately 100,000 people in Germany and 300,000 in North America. In this paper, we will present findings from surveys conducted in the United States and Germany about the healthcare experience of people with MS.

Method: In the United States and Germany data were collected using structured mail surveys. In the US data were collected through national disability, community organizations and listservs as part of a national longitudinal study about the healthcare experience of people with physical disabilities. 161 people with MS (mean age=48.5 years; 72.7% women) participated. In Germany 701 individuals with MS (mean age=49 years; 74% women), members of the German MS Society completed the survey. Response rates exceeded 80%.

Result: All respondents experienced frequent symptoms of spasticity (US: 60%; Germany: 50%) and visual problems (US: 31%; Germany: 50%). Most respondents in both countries had health insurance. Fewer than one-third of the US respondents were covered by public programs (Medicare, Medicaid), 96% of the German participants had mandatory coverage. People in both countries mostly turn to neurologists for MS-related problems (US: 83.9%, Germany: 91.3%), followed by general practionners (US: 36%; Germany: 60.5%). Use of complementary and alternative medicine (CAM) as well as receipt of rehabilitative therapies was more frequent among German respondents.

Conclusion: The data provides the first comparative view of the health care experience of people with MS in two industrialized countries. US and German study participants report similar experiences with healthcare services. Differences exist with regard to primary insurance coverage, the use of CAM and in the receipt of rehabilitative treatments.

Public Health Implication: While transnational comparisons may provide valuable insights into how successful health care systems can impact the lives of people with MS and other disabling conditions, reliable comparison data is limited. Public health needs to move beyond its global focus on acute infectious diseases and direct attention to much needed disability data as more people worldwide live with chronic disabling conditions.

Long Term Effects of Early Intervention With Children Prenatally Exposed To Cocaine

Authors: *A. Claussen, K. Bono, K. Scott*

Background: For infants prenatally exposed to cocaine, biological and environmental factors combine to present high risk conditions for adverse developmental outcomes. The Linda Ray Intervention Project provided three levels of intervention—center based, home based, and primary care (medical and social services) — in a full service, 0-3 early intervention program. At 36 months, intervention effects were significant for cognition, language, gross motor, and behavior, with center based resulting in the most optimal and primary care in the least optimal development (Claussen et al, 2004). However, it is important to know if intervention effects can be maintained long-term, particularly in respect to

prevention of disabilities. The present study examined whether this early intervention would have an effect on children's rate of special education placement when entering elementary school.

Method: For the first cohort (urban, predominantly poor, primarily minority) of children born in 1993-1995 who had completed the intervention at age 3 and who had entered public school by the year 2001-2002, data from school records were retrieved (40 Center, 37 Home, and 14 Primary Care). In addition, 262 records from a database of cocaine exposed children who did not receive any services were used as a comparison sample.

Result: The rates of special education placement for children in the Center, Home, Primary Care,and non-intervention comparison groups were compared using chi-square analysis. The differences between Center based participants (not Home-based? and Comparison children were significant. The Center based group showed a 5% special education placement rate compared to 16% in both the Home based and comparison groups. For Center based, the two cases of special education were for emotional handicaps. For Home based, 3 children were receiving services for speech impairment, 1 for emotional handicaps, and 2 for learning disability. One Primary Care participant was receiving services for speech impairment. For the comparison sample, 19 children were identified as learning disabled, 13 as speech or language impaired, 9 as emotionally handicapped, and 1 as mentally handicapped.

Conclusion: These findings show that for children at risk due to prenatal cocaine exposure the positive effects of receiving center based early intervention services can be maintained on a long term. In contrast, home–based services did not result in a significant reduction of special education need at school entry.

Public Health Implication: For this type of high risk population, center based early intervention services may prevent later disability in a significant proportion of children.

Loratadine (Claritin®) and Hypospadias, Data From The National Birth Defects Prevention Study, U.S.A. 1997-2000

Authors: *J. Reefhuis, M. Honein, R. Olney, M. Werler, C. McCloskey, L. Edmonds*

Background: A Swedish report in the literature indicated twice the rate of hypospadias among male offspring of women who took loratadine during pregnancy compared to the general population. Hypospadias affects approximately 4 in 1,000 infants in the U.S., and a 1998-1999 survey among American women indicated 3% had used loratadine in the previous week.

Method: The National Birth Defects Prevention Study (NBDPS) is an ongoing multi-site case-control study. Infants are identified through existing birth defects surveillance systems in eight states, and mothers are interviewed using a computer-assisted telephone interview in English or Spanish. For this study cases were defined as infants with second or third degree hypospadias. Controls were liveborn male infants with no major birth defects. The primary exposure was defined as any use of loratadine from one month before the pregnancy through the first 3 months of pregnancy. To control for confounding by indication, we also assessed any exposure to non-sedating antihistamines, sedating antihistamines, and asthma medications during the same time period.Potential confounders included in multivariate logistic regression are maternal age, maternal race-ethnicity, birth month and center.

Result: Our study population consisted of 437 male infants with second or third degree hypospadias and 1275 male controls. Among case and control mothers combined 1.7% reported taking loratadine at some time from one month before pregnancy through the end of the first trimester. Univariate and multivariate analyses did not show significant associations between loratadine exposure and hypospadias (adjusted odds ratio 0.89, 95% confidence interval 0.36-2.20). There were also no significant associations between the other medication exposures assessed and hypospadias.

Conclusion: In this large national dataset, the use of loratadine during early pregnancy was not associated with second or third degree hypospadias.

Public Health Implication: While these results do not provide definitive information on the safety of loratadine use during pregnancy, they may be useful for women and health care providers following inadvertent exposures

Maternal Autoimmune and Allergic Diseases and Childhood Autism

Authors: *L.A. Croen, C.K. Yoshida, R. Odouli, J.K. Grether*

Background: Results from two recent epidemiologic studies suggest that a family history of autoimmune disorders is more common among children with autism than healthy control children. First degree relatives, especially mothers, are most often affected.

Method: To explore the association between maternal autoimmune and allergic diseases and childhood autism spectrum disorders (ASD), we conducted a case-control study among children born at a Kaiser Permanente Northern California (KPNC) facility between 1995-1999. Cases (n=407) were children with an ASD diagnosis (ICD-9-CM 299.0, 299.8) recorded in KPNC outpatient databases. We randomly sampled controls (n=2095) from the cohort of births without an ASD, frequency matched to cases on gender, birth year, and hospital of birth. Maternal autoimmune and allergic diseases diagnosed from two years preceding delivery to two years following delivery, as well as information on several maternal and infant characteristics, including maternal medication use in the year prior to delivery, was obtained from health plan and vital statistics databases.

Result: Significantly more case than control mothers were diagnosed with psoriasis (2.7% vs. 0.95%, p=0.003), type 1 diabetes (1.2% vs. 0.43%, p=0.045), asthma (15.5% vs. 10.5%, p=0.003), atopic eczema (3.7% vs. 2.2%, p=0.045), and allergic rhinitis (20.9% vs. 14.5%, p=0.001). The frequency of maternal asthma and allergies increased significantly with increasing numbers of ASD-affected children in the family (asthma: chi-square trend=9.49, p=0.004; allergies: chi-square trend=8.94, p=0.006). After adjusting for maternal age, race/ethnicity, education, medication use, and plurality, maternal second trimester diagnoses of asthma or allergy were twice as common in cases than controls (asthma: OR=1.9, 95% CI 1.0-3.7; allergy: OR=2.3, 95% CI 1.1-4.8).

Conclusion: These results suggest that maternal immune function during pregnancy is associated with risk of ASD.

Public Health Implication: Ultimately, a better understanding of the underlying biology may contribute to the development of early intervention strategies and the eventual prevention of autism.

Maternal Caffeine Consumption and Risk of Cardiovascular Malformations In The National Birth Defects Prevention Study

Authors: *M. Browne, C. Druschel, A. Mitchell, P. Romitti, A. Lin, and A. Correa*

Background: Evidence from animal studies suggests that maternal prenatal exposure to high dose caffeine may cause cardiovascular malformations (CVMs) and other birth defects and, at lower doses, may enhance the teratogenicity of other substances such as nicotine, alcohol, bronchodilators, and phenytoin. Most epidemiologic studies have failed to show an association between maternal caffeine use and risk of CVMs. It is possible that any increase in risk occurs mainly in interaction with other factors and only for certain types of CVMs.

Method: Using data from the National Birth Defects Prevention Study (NBDPS), this study examined whether maternal caffeine consumption during the first trimester increases the risk of CVMs and whether caffeine acts as a "co-teratogen" in combination with maternal smoking, alcohol consumption, or use of certain medications. Approximately 3300 cases and 2900 controls were included in the analysis.

Conclusion: The number of CVM cases in the NBDPS is much larger than in most other epidemiologic studies to date, providing power to detect relatively small increases in risk of malformations. The number of CVM case-infants available for study will also permit analysis of mechanistically similar subgroups of CVMs. Preliminary results of our analysis of the association between caffeine intake and risk of CVMs will be presented.

Public Health Implication: Since pregnant women commonly consume caffeine, even a small increase in the risk of malformations, possibly restricted to subgroups exposed to "co-teratogens," would be an important public health concern.

Maternal Characteristics Associated with Recurrent Adverse Birth Weight Outcomes: Louisiana, 1997-1999

Author: *D. Cooper Payne*

Background: The scientific literature is replete with efforts to identify characteristics associated with individual episodes of low birth weight (LBW, 2500 grams) outcomes. However, few studies focus on

defining risk factors among mothers having recurrent adverse birth weight outcomes, particularly more serious 1500 gram birth weights (VLBW). Diminished fetal growth and shortened gestation are two primary components of VLBW, making it a common proxy for infant mortality, acute morbidity, and developmental disability.

Method: This study identifies characteristics of multiparous mothers delivering an infant weighing less than 1500 grams that are significantly associated with previous LBW outcome in this sample (n=914). Deterministically-linked PRAMS and birth certificate records for Louisiana births (1997-1999) were analyzed using bivariate and weighted multivariate methods to evaluate statistical relationships between maternal characteristics (selected socioeconomic, behavioral, demographic, psychosocial, and medical variables) and consecutive adverse birth weight outcomes.

Result: Among multiparous Louisiana mothers who delivered a live birth weighing <1500 grams, more than one-third (37.9%) previously delivered a LBW infant (Black women 43.5% versus White women 26.0%; Chi Sq. p<0.0001). The adjusted likelihood of experiencing such recurrent adverse birth weight outcomes was associated with Black maternal race (OR=2.482; 95% CI= 1.668, 3.694; p<0.0001), index maternal age <20 years (OR=2.664; 95% CI= 1.169, 6.071; p=0.0197), and index gestations lasting >30 weeks (OR= 1.827; 95% CI= 1.093, 3.056; p=0.0216). Reported cessation of alcohol consumption within three months before pregnancy had a protective relationship with this recurrent outcome (OR=0.357; 95% CI= 0.141, 0.906; p=0.0301).

Conclusion: Multiparous Black mothers with a previous LBW were significantly more likely to have a subsequent <1500 gram birth outcome compared with White mothers. Despite the associations reported here, it remains unclear whether the significance of maternal race, age, and gestation indicate a predisposition for these repeated negative outcomes, or whether an unidentified environmental factor remains absent from consideration. The absence of statistically significant behavioral, socioeconomic, and prenatal care factors that are more commonly reported with singe-time LBW episodes is a notable result.

Mediating Effects of Maternal Interaction on Affect Regulation Among Infants with Prenatal Alcohol Exposure

Authors: *J. Lowe, N. Sheehy Handmaker, C. Meng*

Background: Alcohol exposure during pregnancy causes birth defects. Research has shown patterns of neurobehavioral problems associated with prenatal alcohol exposure in self-regulatory functions associated with control of emotions and behavior. An experimental paradigm known as the 'Stillface" was used to assess infant affect regulation among a sample of alcohol-exposed infants. We hypothesized that the infants born to mothers who drank more during pregnancy would have lower levels of positive affect than infants exposed to less alcohol. Moreover, we expected that infants whose mothers were more interactive during a play period would show better affect regulation following a stressor.

Method: Women who showed risk for fetal alcohol exposure, based on their drinking levels prior to their awareness of their pregnancies, were recruited from obstetric clinics for a NIAAA-funded study. The first 74 infants who completed the 14-month evaluations were included in these analyses. Their mothers reported a mean of 6 drinks per drinking day (DDD) during pregnancy. The mothers' mean age was 25 years. The majority graduated from High School or had completed some education after High School (72%). Most were from minority groups (49% Hispanic, 3% Native American) or Caucasian (39%).

Result: Using the slopes (rather than means) of the infant affect coded for the 120 second periods as the dependent measures, multiple regression analyses revealed that drinking during pregnancy significantly predicted infant affect (r2=.12 , p=.004). Surprisingly, infant affect was higher among mothers who drank more intensely (DDD) during pregnancy for the baseline play session. The strongest predictor of infant affect following the first 120 second stressor (mother's Stillface) was maternal interaction. Infants of mothers who showed more positive interactions during the baseline session had more positive affect during the stressful session (r2=.08, p=.02). Girls whose mothers drank more during the pregnancy showed more difficulty recovering from the stressor, based on a significant interaction between DDD during pregnancy and gender (r2=.07, p=.003).

Conclusion: The study indicated that mother interaction had a mediating effect on affect regulation among alcohol-exposed infants.

Public Health Implication: Training mothers who drank or are at-risk for drinking in positive interactive play with their infants may mediate effects of prenatal alcohol exposure on infant affect regulation and emotional control.

Medical and Developmental Factors Associated with OCD Classes

Authors: *M. Grados, A. Addington, J. Samuels, K. Liang, Ph.D., M. Riddle, O. J. Bienvenu, B. Cullen, R. Hoehn-Saeric, G. Nestadt*

Background: Obsessive-compulsive disorder (OCD) is a psychiatric condition that affects up to 1-3% of the population. It is often co-morbid with tic disorders, including Tourette syndrome (TS). A latent class analysis on a large sample of OCD and controls found a four-class solution (Nestadt et al, 2003). Three classes on a severity gradient were: minimal disorder (I; N=348), OCD with recurrent depression and generalized anxiety disorder (II; N=73), and OCD highly co-morbid (III; N=15). A fourth class, included subjects with OCD, panic disorder/agoraphobia, tic disorder and separation anxiety disorder (IV; N=16) and appeared distinct from the first three classes. We report on the clinical characteristics of OCD class IV as well as the medical and developmental factors that may be associated with the Class I-III gradient or Class IV.

Method: The family study of OCD comprised 796 subjects with 80 OCD probands, 343 OCD relatives, 73 control probands and 300 control relatives. Qualitative analysis of the members of OCD Class IV are presented in table form. Logistic regressions predicted medical and developmental factors in relation to OCD classes. Classes I-III were entered as a severity gradient (values 1,2,3) while Class IV was used in a separate set of logistic regressions as a categorical yes/no variable to predict the presence of medical and developmental factors.

Result: Sixteen subjects classified into class IV were characterized by the presence of Panic Disorder or Separation Anxiety Disorder. Subgroups were OCD + Panic, OCD + tics + Panic; Tic + Panic only and Panic/SAD. Obsessive-compulsive personality disorder (OCPD) was present across subgroups. Among medical factors, frequent throat/ear infections was highly associated with the Class I-III severity gradient ($p < 0.001$). Among developmental factors, clumsiness as a child ($p < 0.001$), being inattentive ($p < 0.01$), being less athletic ($p < 0.05$), dating less often ($p < 0.05$) and having a later puberty ($p < 0.05$) were associated with the Class I-III severity gradient. Only a history of encephalitis/meningitis ($p < 0.05$) and a history of severe headaches ($p < 0.05$) were associated with Class IV.

Conclusion: The distinctive feature of Class IV was Panic Disorder and separation anxiety. Childhood throat/ear infections, clumsiness, inattention, less athletic prowess, less social dating and later puberty were associated with OCD Classes I-III. OCD Class IV was associated with a history of encephalitis/meningitis and severe headaches.

Public Health Implication: Childhood history factors may be associated with higher risk for incidence and severity of OCD in adulthood. Frequent throat/ear infections may be amenable to protective interventions and reflect an immune diathesis. Early intervention in at-risk populations could decrease OCD incidence and severity.

Medical Home Implementation through Community-based, Primary Care Practices; Moving to the Next Level

Authors: *C. Kraft, F. Gallagher, B. Harding*

Background: The Medical Home refers to a structure and process of care which is accessible, family-centered, comprehensive, coordinated, compassionate, and culturally sensitive. The Medical Home recognizes the needs as well as the expertise of families of Children and Youth with Special Health Care Needs (CYSHCN). The goals related to CYSHCN in Healthy People 2010 start with the first goal of every child being cared for in a Medical Home. Primary Care Practices are interested in improving their ability to care for CYSHCN as a Medical Home. Barriers of lack of time, poor reimbursement, and no systematic method of improvement keep Primary Care Practices from achieving this goal. Three Pediatric Practices in Virginia partnered with Care Connection for Children, Virginia's state Title V program. They became a state team as part of the Medical Home Learning Collaborative, conducted by the National Institute for Children's Health Quality (NICHQ) and the Center for Medical Home Improvement (CMHI), and sponsored by the Maternal Child Health Bureau. Each practice worked through the Collaborative to make small, but tangible changes in their ability to work in care partnership with their parents of CYSHCN and with the greater community, health systems design, delivery system design, decision support, and clinical registries for CYSHCN. The state team has now designed a method for spreading the Medical Home improvements to other practices in Virginia.

Method: A state resource team was brought together from the participants in the original three pediatric teams in Virginia. This team designed a series of on-site visits

and team conference calls to work with practices to develop tangible goals and to document improvements in their practices. Each practice filled out a Medical Home Index, a Family Satisfaction Survey, and a Staff Satisfaction Survey at the beginning of the study. Data was collected from each of the practices on number of ER and unplanned hospitalizations for their CYSCHN as well as other quality measurements from families.

Result: Each of the five practices in the statewide spread initiative were able to document tangible improvements in their ability to be Medical Homes for CYSHCN. All five practices demonstrated improvements in their Medical Home Index Score, their family satisfaction survey, and their staff satisfaction survey. Each practice stated that the continued contact and mentorship of the state resource team was vital to their ability to improve.

Conclusion: Primary Care Practices have the capability to make changes in their delivery system design and care partnership in order to support becoming more family-centered. The Medical Home does increase parents' perception of quality of care for their child as well as increasing staff satisfaction. The method of using a trained state resource team in a mentoring, advisory role increases the likelihood that a primary care practice will improve its ability to be a Medical Home.

Public Health Implication: As Medical Homes for CYSCHN improve in number and quality, the overall care for these children will improve. Medical Homes have been demonstrated to decrease expensive utilization such as hospitalizations and emergency room visits, while increasing the overall health parameters of CYSCHN. Medical Home is a family-friendly, cost efficient method of caring for CYSHCN. Training to enable practices to reach the goal of becoming Medical Homes will only improve the health status of all of these patients.

Medication Use In Pregnancy: 1976-2000

Authors: *A. Mitchell, S. Hernandez-Diaz, C. Louik, M. Werler*

Background: Though medication use by pregnant women poses a potential risk to the fetus, there is little information on the prevalence and secular trends of such use. Further, most available data focus on drug classes or indications, but teratogenic effects may differ considerably among drugs within a given class. We therefore describe the secular patterns of medication use by pregnant women over a recent 25 year period.

Method: Between 1976-2000, as part of an ongoing case-control surveillance program designed to assess the risks and safety of medication use in pregnancy, the Slone Epidemiology Center Birth Defects Study interviewed, in the areas surrounding Boston and Philadelphia, 13,749 mothers of infants with a wide range of malformations and 2,379 mothers of infants without malformations. Interviews were conducted within the first six months of delivery, and medication use—both prescribed and over-the-counter (OTC)—was ascertained by detailed questions that involved prompts by indications and specifically-named drugs.

Result: Excluding vitamins and minerals, 85% of pregnant women took at least one medication, and a mean of 2.3 different medication products were taken during pregnancy. Over the 25 year study period, the means of successive 5-year intervals were 1.7, 1.9, 2.3, 2.5, and 2.9 drugs, respectively. While aspirin and Bendectin were among the most common drugs in 1976-80 (30% and 24%, respectively), by 1996-2000 they were not; during the latest period, ibuprofen and pseudoephedrine use were each reported by roughly 20%. Over 25% of the products used contained more than one active ingredient. Of the top 10 drugs used in the 1996-2000 period, 6 were OTC products.

Conclusion: Over the past 25 years, use of medications in pregnant women has been high and has increased, but the specific drugs used vary considerably over time. Since many drugs contain multiple active ingredients, exposure to discreet drugs is greater than that reflected by the "average number of products taken". The most commonly used medications are OTC products.

Public Health Implication: The frequent and changing use of prescription and OTC medications in pregnancy represents a potentially important but underrecognized risk to the fetus. These data help identify priorities for teratologic research.

Methodology for Multiple Source, Poulation-Based Surveillance of the AUTISM SPECTRUM Disorders (ASDs) in the United States ADDM CADDRE Network

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J. Grether, L. Croen, L. Miller, C. Robinson, J. Pinto-Martin, E. Giarelli, S. Levy, J. Daniels, D. Savitz, M. Swanson, K. Scott, M. Yale Kaiser, J. Zimmerman, W. McMahon, R. Kirby, J. Constantino, E. Trevathan, M. Durkin, and M. Katcher

Background: Autism spectrum disorders (ASDs) are defined by unusual and pervasive developmental problems in social interaction, communication, imagination and range of interests or behaviors. Both the epidemiology and etiology of these serious developmental disorders are poorly understood. Estimates of population prevalence vary widely within the U.S. and abroad. Two primary factors contributing to this wide variation in prevalence estimates are 1) differences in case finding and ascertainment methods, and 2) lack of standardization in evaluating diagnostic criteria for ASDs. A more precise estimate of the public health impact of ASDs would serve to inform appropriate and well-coordinated responses by planners at the local and national level.

Method: The 18-state ADDM CADDRE Network is implementing a multiple-source surveillance program to determine population prevalence and characteristics of ASDs and other developmental disabilities. The selected methodology does not rely on professional or family reporting of children's recorded ASD classification and/or diagnosis. Rather, children's files are abstracted at multiple clinical and educational sources and systematically reviewed by an independent team of clinicians in order to determine case status.

Result: This poster illustrates the Network's methodology for identifying suspected cases, abstracting source records, and determining case status. Challenges and accomplishments in database development and training are also described. Selected process evaluation data are presented.

Conclusion: Coordinated public health surveillance of ASDs provides an ongoing source of high-quality data to examine the magnitude and characteristics of ASDs in the population.

Public Health Implication: Surveillance activities conducted by the ADDM CADDRE Network will inform appropriate responses to community and political concerns, promote planning for health and educational services, and generates descriptive data that can foster continued research on ASDs.

Misclassification of Strong Confounders: ART, Folic Acid and the Occurrence of Twin Births

Authors: *O. Devine, R.J Berry, R. Kihlberg*

Background: Adjusting observed association measures to account for confounding is an established procedure in epidemiologic analysis. However, performing this type of adjustment using misclassified surrogate measures of the confounder can lead to substantial bias in estimates of the association of interest. We evaluate this potential bias in light of recent results indicating an association between folic acid (FA) use and twinning.

Method: We used a simulation approach to evaluate the possibility of observing a spurious association between FA use and twinning occurence under assumptions that no such associations truly exists and that correct classification of ART use is not possible. For each simulation, we generated a hypothetical data set including the number of twin births, the number using FA and ART and the value for the surrogate ART measure. We then used these data to calculate the observed Mantel-Haenzsel (MH) odds ratio (OR) linking FA use and twinning and the 95% confidence interval surrounding this estimate.

Result: The simulation results illustrate a severe upward bias in the estimated MH ORs relating FA use and twinning due to adjusting for a mismeasured confounder. When under ascertainment of ART status was set to 40%, the average observed MH OR was 2.29 as opposed to the true value of one. In addition, the confidence interval surrounding these biased estimates excluded the true null of one in 99% of the simulation runs.

Conclusion: Adjustment based on the misclassified values of a strong confounder can result in severely biased estimates of association between the outcomes and predictors of interest.

Public Health Implication: Study results showing an association between FA use, or other variables of interest, and the occurrence of multiple births should be carefully scrutinized to determine the accuracy of reported ART use. Misclassifications of ART status provides a likely explanation for recent results reporting an observed association between FA use and twinning.

Missed Appointment Parameters Among Children and Adults with Disabilities

Author: *P. Sullivan*

Background: Adults and children with disabilities with no health insurance tend to utilize health care services less often than their insured counterparts (LaPlante, Rice, & Wenger, 1995). This failure of adults with disabilities to seek medical attention results in foregoing the basic health services necessary for health maintenance and thereby increases risk of exacerbation of the disability and the development of secondary conditions adding to the severity of the disability (LaPlante et al, 1995). Missed appointments by children with disabilities can have similar adverse effects and may constitute neglect. Given the increased incidence of maltreatment, particularly neglect, among children and youth with disabilities (Sullivan & Knutson, 2000), chronic failure to meet health care appointments may serve as a marker for sentinels of maltreatment among healthcare professionals.

Method: The subjects for this study were patients who missed one or more appointments at a large Midwestern hospital and its six satellite outpatient clinics from January 1, 1997 through December 31, 2000. Throughout this three year time span, the hospital and the satellite clinic sites recorded a total of 12,703 no-shows for medical appointments. From the total number of missed appointments, 10,569 were children and 1,369 were adults. Age data were missing from the records of the remaining 765 patients. Among the no-shows, there were 5,788 boys (54.8%) and 4,781 girls (45.2%) ranging in age from birth to 21 and 621 (45.4%) men and 748 (54.6%) women 22 years and older. The disabled subjects encompassed children and adults with a wide range of disabilities including: psychiatric (combined behavior disorders, attention deficit hyperactivity disorder, and autism); speech and language disorders (combined speech, language, learning disabilities); mental disabilities (combined degrees of mental impairment from severe to profound); orthopedic and health related (combined orthopedic disabilities, and health related disabilities such as asthma, diabetes, and juvenile rheumatoid arthritis); hearing impairments; and visual impairments. There were 4,385 children (41.5%) and 533 (38.9%) adults with disabilities in the sample. Thus, almost half of the children in the sample had some type of identified disability.
The data in this study were obtained from record review of the patient databases in the hospital. All subjects in this research were patients who did not show for one or more appointments. The patient information between 1997-2000 included: patient ID number, no-shows reason (if known), date of no-shows, site of no-shows, insurance provider, and disability status of the patient. Maltreatment status was obtained by a computer merger of the total sample with Nebraska Central Registry and police databases of founded cases of child abuse and/or neglect.

Result: Age:The majority of subjects were children (88.5%) with the remaining 11.5 percent adults seen either onsite or in one of the six satellite clinics. The children ranged in age from birth to 21 and 41.5% were diagnosed with some type of disability. Some 43.9% of the children were neonates to age one and 42.7% had some type of disability. Children between 1 and 4 years comprised 24.1% of the sample and 43.3% had some type of disability. Children between the ages of 5 and 11 accounted for 13.9% of the sample and 39.4% were disabled. The 12-21 age group comprised 6.7% of the sample and 31.2% were disabled. The adult subjects 22 years of age and older encompassed the remaining 11.5% of the total sample and 38.9% were disabled. Age was related to type of insurance provider. Significantly more children were covered by Medicaid programs, private insurance, and commercial HMOs than adults [X^2 (6, N=7,823) = 78.66, p = .000]. Age was also related to disability status and type of disability. Significantly more children were disabled [X^2 (1, N = 11,938) = 3.26, p = .037] than adults. Among the disability groupings, significantly more children had health related/physical disabilities, mental retardation, psychiatric and speech/language or learning disabilities while more adults had hearing or visual impairments [X^2 (5, N = 4,918) = 344.37, p = .000].

Gender: Slightly more than half of the population was male (53.7%) and 59% were disabled. The remaining 46.3% were female and 41% were disabled. Significantly more males had disabilities than females [X^2 (1, N = 12,703) = 96.00, p = .000]. There were also significantly more females enrolled in Medicaid related programs than males [X^2 (6, N = 7,823) = 14.75, p = .022]. There were significantly more females than males in the 22 and older age group and more males than females in the 1 year and younger age group [X^2 (4, N = 11,938) = 56.28, p = .000]. Significantly more males had records of maltreatment than females [X^2 (1, N = 11,938) = 3.16, p = .043]. There were no significant gender differences among the no-show appointments for median family income, reason for no-show, or site of service.

Maltreatment Status: A surprisingly large percentage of patients (22%) who missed appointments had substantiated records of maltreatment in either Central

Registry or police databases. Slightly more than half (55.6%) of the maltreated children were disabled and disability status was significantly associated with maltreatment [X2 (1, N = 12,703) = 29.10, p = .000].As expected, given the linkages between maltreatment and poverty, significantly more of the maltreated children came from families with median incomes less than $30,000 a year [X2 (1, N = 11,238) = 9.08, p = .001]. There were no significant differences between the median family incomes of children with and without disabilities.Among the children with disabilities who missed appointments, there were more maltreated than nonmaltreated children among the following disability groupings: hearing impairment, mental retardation, psychiatric/behavior disorders, speech/language disorders and visual impairment [X2 (1, N = 4,932) = 10.67, p = .001].

Reason for Missed Appointment: There were eight general reasons for the missed appointments recorded and they included illness in family, insurance problems, forgot the appointment, patient feeling better, schedule problems, transportation problems, and weather. Significantly more children with disabilities than without disabilities missed appointments due to illness in the family, parent forgot the appointment, patient was feeling better, scheduling problems, transportation problems, and the weather [X2 (8, N = 12,688) = 35.72, p = .000].Median family income was also related to disability status and reason for missed appointments. Significantly more children with disabilities from families with incomes less than $30,000 per year missed appointments due to insurance problems, forgetting the appointment, transportation problems and the weather than disabled children from families with median incomes greater than $30,000 per year [X2 (8, N = 7,181) = 19.31, p = .013].
Insurance Provider Status: Insurance providers for the no-show patients in this research included Medicaid, Private Insurance, Commercial Non-HMO, Commercial HMO, and No Insurance. There were significant associations between insurance provider status and age, gender, disability status, maltreatment status, and income. Significantly more children were covered by some form of Medicaid, private insurance, or Commercial HMO than adults [X2 (6, N = 78.66) p = .000]. Female patients tended to be covered by Medicaid providers while male patients were more likely to be covered by Commercial Non-HMOs and private insurance [X2 (6, N = 7823) = 14.75, p = .022]. More individuals with disabilities had either Medicaid, Non-Commercial HMOs or no insurance than patients without disabilities [X2 (6, N = 7874) = 33.96, p = .000]. Patients with records of maltreatment were more often covered by Medicaid or had no insurance than nonmaltreated patients [X2 (6, N = 17,24, p = .008]. As expected, patients with median family incomes less than $30,000 a year were significantly more likely to have some form of Medicaid or no insurance [X2 (6, N = 7,428) = 1222.05, p = .000].

Conclusion: This research provided data on patient missed appointments at a metropolitan hospital serving children and adults with six suburban satellite clinics in a Midwestern city. Importantly, data were gathered on several patient variables including age, gender, disability status, maltreatment status, income, and insurance provider. Significantly more children, women, people with disabilities, and people with median family incomes less than $30,000 per year were enrolled in Medicaid related programs. A high baserate of maltreatment (22%) was found among the subjects. There were more maltreated than nonmaltreated children among the following disability groupings: hearing impairment, mental retardation, psychiatric/behavior disorders, speech/language disorders and visual impairment. Significantly more children with disabilities from families with incomes less than $30,000 per year missed appointments due to insurance problems, forgetting the appointment, transportation problems and the weather than disabled children from families with higher median incomes.

Public Health Implication: There is a major gap in the health care literature addressing the gamut of health care parameters (i.e., access, utilization, quality of care, satisfaction with care, and child well being) among children with disabilities. This research suggests that maltreatment status is an important parameter in children with disabilities missing medical appointments. Historically, health care providers have focused on sexual and physical abuse and have overlooked neglect among children. This research suggests that medical neglect should also be an area of focus for health care providers. Forms of medical neglect resulting in actual and potential harm to children with disabilities include lack of health care insurance, underinsurance, limited access to health care by providers who do not accept children on medical assistance, and infrequent utilization of health care services, including missing scheduled medical appointments. Importantly, the primary reasons for missing appoointments identified in this research, namely, insurance problems, transportation, inclement weather, and forgetting the appointment are amenable to interventions.

Modeling Clinical Outcomes of Autistic Spectrum Disorders

Authors: *J. Coplan, A. Jawad*

Background: Autistic Spectrum Disorders (ASD) are etiologically heterogeneous, with highly variable developmental outcomes. We have previously proposed a clinical model of ASD based on 3 parameters: age, degree of atypicality, and level of general intelligence. Here we provide preliminary validation of this model, by quantifying our observation that atypical features show greater improvement over time among children with ASD plus normal intelligence, compared to children with ASD plus comorbid mental retardation (MR).

Method: Retrospective chart review. Setting: tertiary center for evaluation of children with disabilities. Subjects: All children with ASD seen by us since 1997 who met DSM-IV criteria for autism or Pervasive Developmental Disorder, who had undergone at least one administration of the Childhood Autism Rating Scale (CARS), and had at least one determination of Developmental Quotient (DQ) or IQ (N = 91). The sample was 92.3% male, and 80.2% Caucasian. Data Analysis: The Diagnostic and Statistical Manual IVth edition (DSM-IV) of the American Psychiatric Association was used to confirm that each subject met criteria for autism or Pervasive Developmental Disorder (collectively referred to as autistic spectrum disorders, ASD). The CARS was used to quantify severity of expression of ASD. Age, CARS score, and DQ or IQ at each visit were extracted from the medical record. The 2 independent sample t-test or the Mann-Whitney test was used for comparing CARS and age between 2 groups: initial DQ or IQ <0.70 (n=58) versus initial DQ or IQ >or=0.70 (n=33). Associations among CARS score, DQ or IQ, and age, were examined using Pearson or Spearman correlation. A mixed effect model was used for expressing the multivariate model. Length of follow-up (Period) was calculated as (age in months at follow-up)-(age in months at first evaluation). Therefore, at first evaluation, Period = 0. Period was considered as a random effect since collection of repeated information from subjects was not uniform. The predictive relationships among CARS score, age, Period, and DQ or IQ group (<0.70 and >or=0.70) were examined using a mixed effects model. Variables expressed as percent change between first and last measurements were analyzed using the t-test or the Mann-Whitney test.

Result: All 91 subjects met DSM-IV criteria for autism or PDD. Mean age at first evaluation was 46.2 months (SD 23.7; range 20.0 - 167.3 mo.). Mean CARS score at first evaluation was 36.1 (SD 6.3; range 21.5 - 48). Mean DQ or IQ at first evaluation was 0.65 (SD 0.20; range 0.16 - 1.10). CARS scores of children with an initial DQ or IQ <0.70 showed no significant decrement with time. In contrast, CARS scores of children with an initial DQ or IQ >or=0.70 showed a significant decrement with time, which could be modeled by the formula CARS = 31.93 - [(0.12 x age in months at first evaluation) + (0.23 x Period)]. Predicted CARS scores generated by this model correlated with the observed values (r = 0.71), and explained 50% of the variability in the CARS scores for this group.

Conclusion: These data suggest a natural history for ASD that varies by cognitive status, and provide preliminary validation of a statistical model for clinical outcome based on 3 key parameters: age, degree of atypicality, and level of intelligence.

Public Health Implication: This method of modeling outcome, if replicated in a prospective, population-based sample controlled for treatment modalities, will enhance our ability to offer a prognosis for the child with ASD, and will provide a benchmark against which to judge the putative benefits of various treatments for ASD. Our model may also be useful in etiologic and epidemiological studies of ASD, since different etiologies of ASD are likely to follow different developmental trajectories along these 3 parameters.

More Than 25% of Unborn American Babies May Be At Risk of Neurodevelopmental Deficits from Low Maternal Intake of Iodine During Pregnancy

Author: *O. Soldin*

Background: Iodine is an essential component of thyroid hormones necessary for their synthesis. Inadequate iodine nutrition during pregnancy may have adverse and irreversible effects on fetal neurodevelopment. Therefore the status of iodine nutrition of a population is monitored, usually by determination of median urinary iodide concentrations. The objective of this study is to correlate the concentrations of urinary iodide, thyroid hormones and thyroid stimulating hormone (TSH) in an iodine-sufficient population such as the US, in pregnant and non-pregnant women, and to examine if current iodine supplementation in the US during pregnancy is adequate.

Method: Individual thyroid hormone and TSH concentrations in pregnant (n=290) and non-pregnant women that participated in the third National Health and Nutrition Examination Survey (NAHNES III) were correlated to their urinary iodide concentrations.

Result: Based on NHANES III, 25% of pregnant women in the US had urinary iodide concentrations consistent

with an iodine intake below half of the required daily allowance (RDA) during pregnancy.

Conclusion: Adequate iodine availability is critical for fetal neurodevelopment as early as the first trimester of pregnancy. Multivitamin supplementations available in the US that do contain iodine normally provide only 150 ug/day, not the RDA of 220 ug/day and may therefore be inadequate for pregnant women.

Public Health Implication: Since adequate iodine supply is critical during the first few weeks of fetal brain development, 220 ug/day iodine supplementation should be provided to healthy women of reproductive age prior to pregnancy.

Mortality in Duchenne Muscular Dystrophy: An Analysis of Multiple Cause Mortality Data, 1983 to 1997

Authors: *A. Kenneson, Q. Yang, R. Olney, S. Rasmussen, J.M. Friedman*

Method: We analyzed population-based data from death certificates in the Multiple Cause Mortality Files compiled by the National Center for Health Statistics. From 1983 through 1997, 13,095 deaths in the United States were associated with hereditary progressive muscular dystrophy (ICD-9 code 359.1) as recorded on death certificates as underlying cause of death or a contributing factor. ICD-9 code 359.1 includes Duchenne muscular dystrophy (DMD) and other conditions. The age at death in these individuals fell into a tri-modal distribution with peaks at 0, 17, and 62 years, representing congenital, childhood and adult onset cases. In the younger group (0 to 12 years), 37.3% of cases were female, and in the older group (30 to 99 years), 40.6% were female, indicating a predominance of autosomal cases. In the middle group (13 to 29 years), 95.6% of cases were male, which is consistent with the X-linked inheritance in most cases. Males in this group were presumed to have DMD (N = 4857). Proportional mortality rates, underlying causes, contributing factors, and demographic characteristics were assessed in the DMD cases.

Result: DMD deaths were more common among deaths in White males (1 in 3386) than among deaths in Black or African-American males (1 in 4409) ($p = 0.001$) in this age group. The distribution of age at death did not differ between racial groups. State-specific median age at death ranged from 17 to 21 years. DMD-associated deaths occurred at a significantly earlier age in the southeastern United States (median = 19 years) than in other regions of the country (median = 20 years, $p = 0.003$). From 1983 through 1997, there was a small but statistically significant increase in the median age at death for both Blacks or African-Americans and Whites ($p = 0.039$). During that time period, the overall median age at death increased from 19 to 20 years. Factors commonly listed as contributing to death included cardiomyopathy and cardiac dysrhythmias (34.2%), and pneumonia and other respiratory infections (20.8%). Cardiomyopathies and cardiac dysrhythmias were more commonly documented among Black or African-American males (49%) than among White males (32.3%) ($p<0.0001$).

Conclusion: Among Blacks or African-Americans but not Whites, the age at death was younger in individuals with cardiac involvement than in those without cardiac involvement. Based on analysis of these data, DMD appears to account for a lower percentage of all deaths in Blacks or African-Americans and is more often associated with cardiac involvement than in Whites. Challenges in the interpretation of these data include the lack of an ICD-9 code specific for DMD, and potential recording biases in underlying cause of death and contributing factors.

Mother/Infant Genetic Profiles For ADH2 As Risk Indicators For The Development of FAS and FASD

Authors: *J. Powell, K. Squibb, J. Cook*

Background: Fetal alcohol syndrome (FAS) and fetal alcohol spectrum disorders (FASD) represent the largest categories of preventable mental retardation syndromes and birth defects. The prediction of alcohol's in utero effects is complicated by maternal and fetal genetic factors that influence alcohol metabolism. The majority of ethanol is metabolized to acetaldehyde through the primary action of alcohol dehydrogenase (ADH). Genetic polymorphisms in ADH2 result in altered enzyme kinetics and variation in ethanol metabolism, and consequently mediate some of the toxic effects of ethanol and its metabolite, acetaldehyde. Only a limited number of human studies have examined the relationship between maternal and infant genotype, maternal alcohol use, and fetal outcome. The outcomes of these studies have been inconsistent, suggesting that more research is needed to resolve the discrepancies. The objective of this pilot study was to assess whether the maternal and fetal ADH genotypes influence the risk of FAS and FASD.

Method: Maternal and infant genetic profiles, maternal alcohol use, and infant developmental assessments at birth, 6 months, and 1 year were compared in a small group of mother-infant pairs. Genomic DNA was purified from whole blood using a commercial kit. ADH genotypes were determined using amplified product length polymorphism (APLP) and restriction fragment length polymorphism PCR (RFLP-PCR). Alcohol consumption by the mother was determined through the AUDIT questionnaire and the infant assessments included standard and FAS-specific physical parameters, a mental skills evaluation, and a motor skills evaluation.

Result: As evidenced by the smaller AUDIT scores, pregnant women with the ADH2*3 allele were significantly more likely to be teetotalers or light drinkers (odds ratio=0.75) than those with the ADH2*1 allele. An overwhelming majority, 84.6%, of those with the ADH2*1 allele were found to be present in the moderate to heavy drinking group. As a consequence of increased alcohol use, the ADH2*1 mothers produce infants with a higher risk for alcohol damage as suggested by an increased incidence of intensive care hospitalization and growth retardation.

Conclusion: An insufficient number of infants have been born and evaluated to achieve significance.

Public Health Implication: The elucidation of maternal ADH genotypes that are predictive of maternal alcohol use and indicative of infant outcome is important in instituting interventions to diminish the incidence of FAS and FASD. In addition, determination of those infant genotypes exhibiting alcohol sensitivity would be invaluable in recognizing an increased risk of FAS and FASD in infants exposed to alcohol in utero.

MTHFR Polymorphism, Epigenetics, and Risk For Autism

Authors: *M. D. Fallin, D. Avramopoulos, P. Zandi, C. Newschaffer*

Background: Although evidence clearly suggests that genetic factors play an important role in autism, no autism-related genes have been conclusively identified. This is likely due to a complex etiology that involves genetic, epigenetic, and environmental influences during development. Epigenetic influences, such as methylation-controlled imprinting have been implicated in related disorders such as Angelman's syndrome and fragile X, although evidence for imprinting effects in autism is still equivocal, with findings of both paternal or maternal inheritance, depending on the study and genomic region. If imprinting is an important mechanism, methylation should be an important mediator. Therefore, genes such as MTHFR, which affect DNA methylation, may contain variation associated with the expression of autism.

Method: We are genotyping a sample of 370 autism trios (an affected child and both parents) collected by the Autism Genetics Resource Exchange (AGRE) at the C667T polymorphism of the MTHFR gene, which is known to affect enzymatic activity and correlate with DNA methylation. We will use the log-linear modeling approach of Weinberg to address four hypotheses: 1) that the C667T genotype carried by an autistic child is associated with risk, 2) that there is a parent-of-origin effect of this risk, 3) that the C667T genotype carried by an autistic child's mother is associated with risk; and 4) that the C667T genotype carried by an autistic child's father confers risk.

Result: We will present estimates of effect for each of the four hypotheses – risk associated with the child's MTHFR genotype, any parent-of-origin effect on this risk, and the risk associated with mother's or father's MTHFR genotype. In addition, interactions between child and maternal MTHFR genes will be explored and presented.

Conclusion: Findings of an association with MTHFR genotype lend support for the role of epigenetic effects in autism etiology, and imply that genetic studies of other regions would be remiss to not include epigenetic possibilities in assessment of genetic predisposition to ASD.

Public Health Implication: Epigenetic control, and DNA methylation specifically, may be important mechanisms in genetic risk for ASD. If true, genetic risks must be assessed in this context, since carrier status alone would not predict risk, but rather the parent of origin and the methylation patterns during replication must be considered. Also, if methylation plays a fundamental role in expression of risk genes then molecular substrates in the methylation pathway, such as foate, may also be important.

Multi-Center Study for Birth Defects Monitoring Systems in Korea

Authors: *J. Yang, Y. Kim, J. Chung, M. Kim, H. Ryu, H. Ahn, J. Han, S. Yang, A. Kim, K. Koh, B. Yoon*

Background: Epidemiological data about congenital malformations is of vital importance to scientific research on pathomorphogenesis, aimed at prevention and public health education. Currently, no nationwide birth defect monitoring system exists in Korea. Our aim is to establish a multi-center birth defects monitoring system for evaluating the prevalence and the serial occurrence of birth defects in Korea. This work was supported by the Korea Food Drug Administration Grant. KFDA- ED 2002-21.

Method: Ten centers participated in this monitoring work program. A trained nurse actively collected the records obtained from delivery units and pediatric clinics in participating hospitals monthly. We observed 1,537 birth defect cases among 86,622 deliveries, which included live births and stillbirths.

Result: The prevalence of birth defects was 1.8%, and the sex distribution of the birth defect cases was male 55.2% and female 41.6%. The highest proportion of birth defects was 17.5% in cardiovascular system, and the second most common birth defects involved genitourinary system (15.6%). Chromosomal anomalies were detected 30.0 per 10,000 births. Of these chromosomal anomalies, Down syndrome was ranked first.

Conclusion: This study led to the establishment of a multi-center active monitoring system for birth defects and could provide good quality information on birth defect data in Korea.

Public Health Implication: For monitoring of the serial occurrence of birth defects, it is necessary to increase the number of participating hospitals and to launch a nation-wide multi-center study.

N2-Ethylguanine DNA Adduct As A Risk Indicator for FAS and FASD: A Case Study

Authors: *S. Gelhaus, W. LaCourse, J. Fishbein, P. Blans, K. Squibb, and J. Cook*

Background: Fetal alcohol syndrome (FAS) and fetal alcohol spectrum disorders (FASD) represent the largest categories of preventable mental retardation syndromes and birth defects. It is theorized that ethanol's toxicity is in part mediated by damage to DNA. In DNA, ethanol's primary metabolite, acetaldehyde forms an N2-ethylguanine DNA adduct. The duration of this adduct, its affect on DNA replication, and its repair mechanism are currently unknown. A case study is presented to assess N2-ethylguanine as a potential alcohol biomarker with possible clinical utility in predicting the risk of FAS/FASD in infants born to alcohol-using women.

Method: The case subject was a 20 year old who reported binge drinking on hard alcohol for the first 5 weeks of her pregnancy. The separation and quantification of N2-ethylguanine from unadducted nucleosides was performed by an in-house protocol. DNA was purified from whole blood using a commercial genomic DNA purification kit. The isolated DNA was completely hydrolyzed into monomer bases using established digestion procedures to liberate purine bases; recovery of the purine bases was >96%. The N2-ethylguanine DNA adduct was isolated and quantified by reversed phase HPLC with isocratic elution and UV/fluorescence detection. Bases were identified by retention time and by standard spiking. Base quantitation was by calibration curves of standard peak height signals.

Result: The identification of N2-ethylguanine by HPLC was confirmed through standard spiking and LC/MS. HPLC precision for the N2-ethylguanine was 0.2% for peak area or 3.9% for peak height. Standard curve linearity was in the mmol range ($r = 0.9999$). Preliminary analytical sensitivity was 29 nmol (HPLC/UV detection), 2.9 nmol (HPLC/fluorescence detection), and 20 fmol (LC/MS). No interference was found from free bases. The subject's N2-ethylguanine concentration determined by LC/MS at 20 weeks gestation was 11.7 pmol/mg DNA, which declined to 8.3 pmol/mg DNA by 30 weeks. Her adduct levels were higher than a comparison nonpregnant social drinker whose N2-ethylguanine concentration was 6.9 pmol/mg. Further studies are in progress to determine the statistical significance of subject data. The subject's fullterm daughter was in the 75th percentile for weight, 17th percentile for length and 10th percentile for head circumference, an indicator of FAS.

Conclusion: Initial studies indicate the acceptability of this method for the separation and detection of purines, including the N2-ethylguanine. Additional subject data is needed to confirm the adduct's clinical utility.

Public Health Implication: Clinical validation of N2-ethylguanine as a biomarker for alcohol damage will fortify the established panel of alcohol biomarkers, aiding in the identification of pregnancies at risk for FAS/FASD and elucidation of the mechanisms of alcohol pathology.

Necessity To Establish A Risk Reduction System For The Mothers Who Are Concerned About Their Childrens' Adverse Health Effect By Chemicals Exposure - A Survey Study In Japan

Authors: *E. Todaka, K. Ogura, O. Masayoshi, M. Omori, H. Osada, K. Aida, H. Fukata, C. Mori*

Background: Recently, concern about the health effect of chemicals has arisen because people are more anxious about them than they used to be. Especially, it seems that mothers are worried about the effect on their children. To understand the awareness of fertile women regarding the health effect of chemicals, we conducted a survey to the mothers who visited public health center for 3-year-old health examination of their children in Japan.

Method: In 2003, Public Health Center of Chiba City sent questionnaires to the mothers who would visit the center for three-year-old health examination of their children in Chiba, Japan. The questionnaire is anonymous and consisted of 14 questions.

Result: The total number of questionnaires sent was 1069, and 261 questionnaires were returned (24.4%). 17% of the mothers were in their twenties, 71% in their thirties, and 11% in their fourties. The analysis of the answers revealed that mothers are much more concerned about their children's health than their own. 89% of the mothers had anxiety about the health effect of endocrine disruptors and dioxins, and 32 out of 72 free descriptions were about the anxiety about children's health. The reasons why they were anxious were reports by media (79%), actual health effect of themselves or their friends (6%), actual use of various chemicals (15%). 38% of the mothers would like to know the concentration levels of chemicals in their bodies, and 44% would like to know if there is any possible care in case they were highly contaminated. On the other hand, the percentages changed to 34% and 52%, for their children. 51% of the mothers would like to know the concentration levels of themselves if it was free of charge. 36% of them would like to know if it was under 5000 yen (about US$50), and 11% would like to know if it was under 10000yen (US$100), and 2% would like to know if it was under 20000yen (about US$200). No mother would pay more than 20000yen for themselves. However, the percentages changed to 35%, 44%, 17%, 3% and 2% for their children (Average income per year of women in their thirties and forties in Japan is about $60,000 to $70,000).

Conclusion: The study revealed that about one out of four mothers are anxious about the adverse health effect from chemicals exposure. They were more concerned about their children's health than their own and they were willing to know the concentration level of their children if there is any possible care. However, if there is no care, they do not want to know the contamination.

Public Health Implication: It became clear that fertile women are concerned about the health effect of chemicals, especially to children, and they would not like to know the concentration level of the chemicals in body if there is no possible care in case they are highly contaminated. It is necessary to establish a system to reduce the chemicals in human body, so that mothers can decrease the concern about their children's health. This work was supported by the fund for endocrine disruptors from the Ministry of the Environment, Japan.

Neonatal Screening Program By Tandem Mass Spectrometry In A Mexican Population

Authors: *L. Martinez, R. Torres, R. Consuelo, M. Alberto, J. Villarreal*

Background: In Nuevo Leon, a state located at northeast Mexico, early detection of IEM was initiated in year 2000 by means of urine metabolic screening, with many difficulties to obtain samples and a high rate of false positive results. In March 2002, the State government invested in a Tandem Mass Spectrometer (MS/MS) and an expanded NS program was initiated. Here we report the results of the first 20 months of operation, detailing our experience, outcome data, and problems faced.

Method: Dried blood-spot specimens (DBS) were collected on S&S filter paper from newborns at 24 hours after birth. Analysis of acylcarnitines (AC) and amino acids (AA) was performed in a Wallac MS2 triple quadruple spectrometer (Perkin Elmer). AC and AA were measured in whole blood (ƒÝol/L) against a mixture containing 12 deuterated stable isotopes for AC and AA respectively (Neogram Kit). Cutoff values were calculated from 10,000 samples. Normal reference values, warning high and low and "urgent contact" values, as well as ratios, were obtained. Babies were resampled after an abnormal result was obtained in the retest of the first sample. Since the beginning, we have been participating in the CDC Newborn Screening QA Program. Babies are also screened for galactosemia.

Result: In the first 20 months we screened 39,843 newborns. One thousand forty five (2.6%) were abnormal and a second sample was requested, obtaining only 82.9% of second samples. Abnormal AA values accounted for most of the positive results in the first sample (tyrosine, aspartic acid and citruline). Free carnitine and 3-OH isovalerylcarnitine were the most common abnormal AC values found. Newborns were evaluated for a Pediatrician and confirmatory tests were done. We have six confirmed cases: Hyperphenylalaninaemia, Citrulinemia, Homocystinuria, tyrosinemia, 3-methylchrotonyl CoA carboxilase deficiency and a case with high levels of 3-OH isovalerylcarnitine. We have been following several cases of transient galactosemia.

Conclusion: The estimated incidence of IEM in our state is 1 in 5000. Early detection of cases had let us to initiate treatment allowing prevention of early deaths, life threatening events and permanent neurological disorders. We need to lower false negative results and to increase recovery of second samples.

Public Health Implication: Prevention of infant mortality and disability is a matter of equity. This is the first expanded NS program in Mexico and it is free for the low income population.

New Estimates of the Effect of Prenatal Smoking on the Risk of Heart Defects

Authors: *S. Williamson, M. Ganz*

Background: Though the problem of congenital birth defects is rare compared to low birth weight or preterm delivery, heart defects comprise a significant health problem in terms of infant mortality and morbidity. Few studies have explored the link between maternal smoking during gestation and congenital heart defects, and results have been inconsistent. Although Woods et al. (2001) found an increase in cardiovascular abnormalities in babies born to smokers, Kallen (1999) found more tenuous results when examining this relationship.

Method: Using the 1996 Perinatal Mortality Data File, a 1:4 case-control design was implemented matching cases (n=3307) to controls (n=13228) on state of delivery and maternal birth year. Linear probability models were used (standard errors adjusted for heteroskedasticity) to estimate the effect of prenatal smoking on the risk of heart defects controlling for maternal education, race, marital status, weight gain, diabetes, infant sex, gestational age, birth order, and adequacy of prenatal care. State-level average cigarette prices were used to obtain instrumental variables (IV) estimates of the effect of cigarette smoking on the probability of a heart defect. The IV regression technique is a quasi-experimental way of reducing the effects of omitted variables that may confound the relationship between smoking and the risk of heart defects.

Result: The number of cigarettes smoked during pregnancy was found to be weakly, though positively and statistically significantly related to the probability of a birth with a heart defect ($P<0.01$). However, this effect was found to be statistically indistinguishable from zero in the instrumental variables estimation ($P=0.28$). In both models maternal alcohol use, race, infant sex, gestational age, and diabetes were found to be significantly related to heart defects, although only the effects of sex, gestational age, and diabetes remained statistically significant in the IV analysis.

Conclusion: Results of the instrumental variables model provide evidence that the effects of smoking, within the context of using vital statistics data, may not be as important a predictor of heart defects as unmeasurable confounders.

Public Health Implication: Reducing smoking is important, but other factors are equally, if not more, important. Future research should examine traditionally unmeasured factors such as the impact of regional well-baby campaigns addressing such issues as maternal nutrition and folic acid intake.

New Jersey Answers for Autism Survey: Initial Findings From An ASD Database

Authors: *W. Zahorodny, M. Brimacombe, J. Vidal, V. Rodriguez, G. Potito, M. Smith, K. Cirlincione, F. Desposito*

Background: Many gaps exist in the scientific understanding of autism. The New Jersey Answers for Autism Survey (Survey) was designed and implemented as a comprehensive, longitudinal, Autism Spectrum Disorders (ASD) database. Survey goals are to specify ASD subtypes, identify possible ASD risk factors and monitor the expression of autism in many persons over time.

Method: A Survey questionnaire representing multiple dimensions of developmental, medical and functional status of persons with ASD was developed, piloted,

revised and implemented. Survey participation is voluntary and limited to New Jersey residents. Preliminary, descriptive, findings derived from Survey participants enrolled between June 2002 and December 2003 are presented.

Result: 943 Survey participants were enrolled. Early analysis of Survey data shows a 4:1 male:female sex ratio, with subjects ranging from 2 to 63 years. 305 Survey subjects (32%) were age 0 to 5 years old; 353 Survey subjects (38%) were 6 to 11 years old; 142 Survey subjects (15%) were 12 to 17 years old. The Survey population reflects the diverse racial and cultural profile of the state (77% Caucasian, 7% African American, 4% Asian, 8% Latino, 4% multi-racial). The Survey population includes 434 persons with Autistic Disorder (46%), 368 persons with Pervasive Developmental Disorder (PDD) and 103 persons diagnosed with Asperger's syndrome (11%). The early expression of ASD (0-2 years) includes abnormal eye contact during the first year (28%), colic (36%), unusual responsiveness to sound (40%) and hypotonia (41%). Survey data indicate that plateau (arrest) of language and social interest occurs more frequently among persons with ASD (67%) than does regression of social interest (13%) or language (18%). The developmental plateau associated with ASD can occur between 7 and 12 months (11%), between 13 and 24 months (61%) or between 25 and 36 months (20%).

Conclusion: The New Jersey Answers for Autism Survey (Survey) captures a broad array of information about the developmental course of ASD from a large sample of affected persons. Preliminary analysis of Survey data underscores that key aspects of autism are observable during the first two years of life and usually include developmental arrest, rather than developmental regression.

Newborn Screening For Duchenne Muscular Dystrophy - Recommendations of an Expert Panel

Authors: *K. Kolor, A. Kenneson, E. Brann, C. Boyle*

Background: Duchenne muscular dystrophy (DMD) is a progressive, X-linked recessive neuromuscular condition that affects about 1 in 3500 to 1 in 5000 male births, making it the most common of all muscular dystrophies. Although the parents of sons with DMD may notice psychomotor delay in their child beginning as early as 6 months of age, an accurate clinical diagnosis is often delayed until the child is 4 to 5 years of age. DMD can be detected with reasonable sensitivity and specificity in presymptomatic newborns (those less than one month of age) by testing dried blood for elevated creatine kinase activity. Preliminary studies indicate that a majority of parents of children affected with DMD support the implementation of newborn screening. Nevertheless, newborn screening for DMD does not currently meet the traditional screening criterion of demonstrated clinical benefit to the affected individual; thus, routine population-based newborn screening for DMD is currently not standard of care in the United States.

Method: During March 2004, a workgroup comprised of recognized international leaders involved in DMD research, clinical practice, public health, ethics and newborn screening was convened in Atlanta, GA. The workgroup was asked to review and evaluate: (1) the benefits and risks of screening newborns for DMD for individuals, families and society, including the available evidence regarding efficacy of early intervention, (2) the experiences with past and present DMD newborn screening programs, with particular attention to informed consent issues, the clinical follow-up of individuals identified with DMD, and the psychosocial needs of affected individuals and their families, and (3) the clinical, laboratory, epidemiologic, and healthcare delivery data currently available related to newborn screening for DMD. Specific areas where more research is needed were identified.

Result: The panel discussions and resulting recommendations served as the basis for the development of a comprehensive research agenda that will inform eventual public health policy decisions in regard to the feasibility of DMD newborn screening in the United States.

Conclusion: The results and recommendations of the workgroup will be presented.

Public Health Implication: Although several DMD newborn screening programs have been implemented in other nations and pilot programs have been performed in the United States, the clinical, psychosocial and economic justifications for population-based newborn screening for DMD remain controversial. The conclusions of the workgroup are intended to guide a research agenda to ensure that newborn screening for DMD is carefully validated prior to any recommendation in regard to integrating the test into standard public health practice.

NTP Center for the Evaluation of Risks to Human Reproduction: The First Five Years

Authors: *G. Jahnke, A. Iannucci, A. Scialli, M. Shelby*

Background: The NTP Center for the Evaluation of Risks to Human Reproduction (CERHR) was established by the National Toxicology Program (NTP) and the National Institute of Environmental Health Sciences (NIEHS) in 1998 to address the impact of chemical exposures on human reproductive and developmental health and to serve as an environmental health resource for government agencies and the public.

Method: CERHR evaluations involve the critical review of reproductive, developmental, and other relevant toxicity data by independent panels of scientists. The public has opportunities to nominate chemicals to CERHR, to recommend scientists to serve on expert panels, and to provide oral comments at the panel meeting and written comments on the draft and final panel reports. The NTP evaluates these comments, the conclusions of the expert panel, and any new data not available at the time of the panel meeting, and prepares a NTP brief describing in plain language NTP's conclusions on the reproductive and developmental hazard from exposure to the chemical.

Result: The primary products of the chemical evaluations are the expert panel reports and NTP monographs. The expert panel report, public comments, and NTP brief comprise the NTP monograph. Over the last five years, CERHR has conducted expert panel meetings, published expert panel reports, and prepared NTP monographs on seven phthalates (DEHP, DINP, DIDP, DnOP, DnHP, DBP, BBP), methanol, 1-bromopropane, 2-bromopropane, ethylene glycol, propylene glycol, and fluoxetine (Prozac®; Sarafem™). Additionally, CERHR conducted a 2-day workshop on the role of thyroid hormones in reproductive and developmental health.

Conclusion: This presentation highlights NTP conclusions on the chemicals evaluated to date.

Public Health Implication: CERHR serves the public as resource for scientifically sound information on reproductive health. The CERHR web site (http://cerhr.niehs.nih.gov) provides access to reports and NTP monographs and information on reproductive health topics. CERHR reports can also be obtained by contacting the CERHR office at NIEHS. (Supported in part by the National Institute of Environmental Health Sciences Contract N01-ES-35503).

Oases In The Food Desert: Working Toward Access To Healthy Food For People With Disabilities

Authors*: S. Kinne, D. Patrick, A. Cheadle*

Background: Recent work has demonstrated the existence of 'food deserts' in cities, areas in which residents without private cars have difficulty getting to large grocery stores with low prices and wide food selection. Ease of access to a store selling fresh and inexpensive produce has been shown to correlate with fruit and vegetable consumption among older adults and people with disabilities. To support healthy eating in these and other vulnerable populations, it is important to identify food deserts as part of community development, and to site public and low-cost housing in places that have good access to grocery stores.

Method: As part of CDC-funded research developing measures of neighborhood accessibility, 12 neighborhoods in two Washington State cities were mapped using Geographic Information Systems (GIS) methods that identified residential zones in which there was accessible fixed route transit access to large grocery stores. An observational tool was developed to characterize the degree to which these and smaller food stores were accessible to people with mobility, hearing and vision limitations. Mapped 2000 Census data on residential concentrations of older adults and people with disabilities showed how well these areas were served by transit that also served large grocery stores. The presentation will demonstrate how mapping identified these areas using publicly available data and simple GIS software.

Result: Neighborhoods varied in the degree to which they provided easy transit access to large and accessible grocery stores. In seven Seattle neighborhoods, 5% to 37% of single-family houses, 9%-51% of duplexes and triplexes, and 35-71% of multi-family apartment buildings had good transit access. Patterns of availability varied; the neighborhood with the lowest access by single family residents had the best access for those in multi-family apartment buildings.

Conclusion: For those without use of an automobile, food deserts were found in both cities, many encompassing areas with high concentrations of older adults and those with disabilities.

Public Health Implication: There are several ways to reduce the impact of food deserts, including supporting the location of grocery stores in under-served areas and

insuring that they comply with ADA access codes, and siting more low cost and accessible housing in places served by public transit. These are not traditional public health activities, but public health's increasing awareness of the importance of community environment for health suggests that it can help supply information to promote these policy initiatives.

Obesity, Quality of Life And Disability Among Youth: A Report from the Washington State Healthy Youth Survey 2002

Authors: *T. Topolski, D. Patrick, and S. Kinne*

Background: The overarching Healthy People 2010 goals are to increase quality and years of healthy life and to eliminate disparities for people with disabilities. Few data for tracking health indicators for persons with disabilities have been available, especially for youth. Two things have hindered youth data collection: 1) lack of a validated disability screener and 2) inadequate measures for tracking health. In 1997, the Seattle Quality of Life Group developed and validated a 4 item self-report youth disability screener (Youth-DS) and a measure of youth quality of life (YQOL-S) for use with youth ages 11-18. The quality of life (QoL) framework has the potential of being a good health indicator for youth because it incorporates both positive and negative aspects of health and well-being. It also captures salient aspects of health other than physical health, such as sense of self, social relationships, environment and culture, and life satisfaction. Additionally, it can be used to integrate multiple internal (e.g. self-esteem and social isolation) and external (e.g., peer and neighborhood influences) factors.

Method: In 2002 Washington State Department of Health fielded the Health Youth Survey, which is administered to youth in a statewide random sample of all public schools with grades 6, 8, 10 and 12. Measures in the survey included: Youth-DS, the YQOL-S (used with a subset of 8-12 graders), and height and weight for computation of "overweight" (top 15% BMI).

Result: The overall response rate was 71% of the schools and 53% of students, yielding valid surveys from 50% of the students enrolled in participating schools. The rate of self-reported disability observed in 8 – 12 graders was 22%. Youth in 6th grade were only asked about activity limitation, which was endorsed by 7% of the youth. Overall 17.4% of youth had BMI scores in the top 15% for their age and gender. Significantly more youth with disabilities (20%) were in the top 15% of their BMI category and youth with disabilities reported significantly lower QoL scores.

Conclusion: Obesity is a growing problem among Washington State Youth, with significant health implications. Quality of life is a valuable, measurable concept that may help to differentiate teens at risk for long-term health problems associated with obesity and poor eating habits.

Public Health Implication: It is important to find factors associated with obesity among youth with disabilities so that effective interventions can be designed to help reduce the proportion of youth who engage in these behaviors.

Omphalocele and Gastroschisis: Black-White Disparity in Infant Survival

Authors: *H. Salihu, Z. Aliyu, B. Pierre-Louis, F. Obuseh, C. Druschel, R. Kirby*

Background: Racial/ethnic variations in the occurrence of abdominal wall defects have been previously noted but it remains poorly understood whether race/ethnicity is a determinant of survival among affected infants.

Method: This study was conducted on cases of gastroschisis and omphalocele recorded for the years 1983-1999 at the New York Congenital Malformation Registry. Adjusted and unadjusted hazard ratios were generated from a Proportional Hazards Regression model to compare survival among affected Blacks, Hispanics and Whites. The major end point of analysis was differences in all cause mortality among infants with abdominal wall birth defects across different racial/ethnic groups.

Result: Among the three racial/ethnic groups, 1481 infants were diagnosed with either omphalocele (978 or 66%) or gastroschisis (503 or 34%). Overall infant mortality rate (IMR) was 182 per 1000, with 74% of the deaths occurring within the first 28 days of life. Omphalocele infants had significantly higher infant mortality (IMR = 215 per 1000) than infants with gastroschisis (IMR = 118 per 1000)[$p < 0.0001$]. Overall, Black infants with abdominal wall defects had lower mortality indices than Whites and Hispanics. However, when considered as separate disease entities, Black infants were twice as likely to survive as compared to Whites if they had omphalocele [Adjusted Hazard Ratio (AHR) = 0.52; 95% Confidence Interval (CI) = 0.37-0.74], and twice as likely to die as Whites if they had

gastroschisis instead (AHR = 2.23; 95% CI = 1.16-4.28). For both defect subtypes, Hispanics have comparable risk for infant mortality as Whites.

Conclusion: The natural history of omphalocele and gastroschisis co-varies with race. Black infants with gastroschisis have worse survival outcomes while those with omphalocele have better chances of survival than their White counterparts.

Public Health Implication: These findings have implications for programs involved in setting and executing strategies to reduce racial/ethnic disparities in survival among groups with developmental defects.

Overview of the Modified Checklist for Autism in Toddlers (M-CHAT)

Authors: *T. Dumont-Mathieu, L. Wilson, P. Dixon, J. Kleiman, J. Pandey, H. Boorstein, E. Esser, S. Allen, M. Barton, J. Green, G. Marshia, D. Robins, D. Fein*

Background: Autism is a neuro-developmental disorder currently estimated to affect between 1 in 250 and 1 in 1000 children. Studies suggest that parental concerns typically begin between 15 and 22 months of age, yet autism/PDD is often identified after age 3. Several studies have demonstrated that early intervention influences outcome. The Modified Checklist for Autism in Toddlers(M-CHAT)(Robins et.al., 2001) is one of the few published early screening tools for autism.

Method: The M-CHAT is a 23 item (yes/no) parent report checklist developed to screen children ages 16 to 30 months old. It can be used in unselected populations (children presenting for a health maintenance visit) or children at higher risk of having a developmental disorder (children referred for early intervention services). Children who fail the M-CHAT receive a confirmatory follow-up telephone call. Those who fail both the initial screening and the telephone follow-up are evaluated using the Autism Diagnostic Interview (ADI), Autism Diagnostic Observation Schedule (ADOS), Childhood Autism Rating Scale (CARS), Mullen Scales of Infant Development, Vineland Adaptive Behavior Scales and the DSM-IV criteria.

Result: To date, a total of 2570 children have been screened by their primary care provider, or their early intervention service provider. Of those screened, 163 have been confirmed as failing the M-CHAT by a telephone interview and provided with an evaluation. Of the 163 evaluated, 120 were diagnosed with an Autistic Spectrum Disorder, 36 with language or global developmental delay, and 7 with other diagnoses such as ODD or ADHD. Current estimates of sensitivity and specificity for the M-CHAT are 0.97 and 0.87, respectively.

Conclusion: Although studies remain underway, to date the M-CHAT is a reliable means of conducting early screening with children ages 16 to 30 months old.

Public Health Implication: It is becoming clear that early intervention is the best response to Autistic Spectrum Disorders. As such, developing a reliable tool for screening all children under three for these disorders is imperative. Early diagnosis allows for early intervention and the resulting improvements in the child's functioning.

Parental Perceptions of Pediatric Care In The Hispanic Population: English vs. Spanish Speaking

Authors: *M. López, R. Perou*

Background: According to the 2000 US Census, there were 12.3 million Hispanics under the age of 18-the largest and most rapidly growing minority group in the United States. Given the increasing number of this population, Health Care Providers (HCP), researchers and health care policy makers are more likely to encounter Hispanic children in their practices, studies, and legislative agendas. The current literature is sparse with respect to information on the pediatric care of Hispanic children. This poster presents some descriptive information on Hispanic parental perceptions of pediatric care and examines the potential role of language.

Method: Descriptive analyses were conducted using the 2000 National Survey of Early Childhood Health (NSECH), a random-digit dialed population-based telephone survey. The principal aim of the NSECH is to assess parental perceptions of pediatric care for children 4 through 35 months of age. Hispanics were oversampled in order to obtain a sufficient sample size. Significance was assessed using Pearson Chi-square and Fisher's Exact Test.

Result: The Hispanic sample totaled 728 participants. Within this group, 54.5% Spanish-language interviews, and 45.5% English-language interviews were completed. Most respondents were mothers (91.7%). Compared with English-speaking Hispanics (ESHs), Spanish-Speaking Hispanics (SSHs) were more likely to report

lower maternal education (less than 12th grade; 59.7% vs. 21.2%; p<0. 01) and unemployment (58.4% vs. 44.2%; p<0.05). SSHs were less likely to have a regular HCPs (68.4% vs. 51.4%; p<0.0001). SSHs were more likely to report that the HCPs never asked how they felt as a parent (49.2% vs. 28.1%; p<0.0001). While ESHs were more likely to have received information in the previous 12 months about child development (46.0%-75.5 % vs. 34.2% -61.3%; p<0.05), SSHs were more likely to find that information helpful (77.0%-97.6% vs. 36.0%-62.2%; p<0.05). Finally, SSHs more often indicated that the HCP had conducted a developmental assessment of their child (48.6% vs. 35.6%; p<0. 01).

Conclusions: There appeared to be a difference in perception of the quality of pediatric care between ESHs and SSHs. While differences were observed, additional analyses should be conducted adjusting for potential confounding variables (e.g., level of education, parity).

Public Health Implication: This study underscores the importance of evaluating additional factors when dealing with the Hispanic population. These analyses could provide insights into strategies of services and health policies to improve the health of Hispanic children.

Parental Reports of Child Disability: Data From The 2001-02 National Health Interview Surveys

Authors: *P. Pastor, C. Reuben*

Background: Activity limitation due to chronic physical, mental, or emotional disorders or deficits is a disability measure that gauges a child's ability to perform major age-appropriate activities such as play for preschool children and schoolwork for older children. The present study examines the association between a child's demographic characteristics (age and sex) and parentally reported activity limitation.

Method: The National Health Interview Survey collects data on children's health and disabilities in addition to information on the demographic characteristics of children and their families. Activity limitation is identified by parental reports of specific limitations in play, self-care, walking, memory, and other activities, and the current use of special education or early intervention services. Parents also identify chronic physical, mental, or emotional conditions causing limitation. In 2001, the list of conditions presented to parents as possible causes of activity limitation was expanded to include specific disorders related to learning and behavioral problems.

Result: In 2001-02, approximately 7% of children less than 18 years of age were reported to have an activity limitation due to a chronic condition. School-age children were more than twice as likely as preschool children to have an activity limitation (8% for children 5-11 yrs and 8.5% for those 12-17 yrs versus 3% for children <5 yrs). The difference between preschool and school-age children in the percent with an activity limitation was due primarily to the large number of school-age children identified as limited solely by their participation in special education. Leading causes of activity limitation varied markedly by children's age: for those 0-5 yrs: speech problems, asthma, mental retardation, 5-11 yrs: learning disabilities (LD), Attention Deficit Hyperactivity Disorder (ADHD), and speech problems, 12-17 yrs: LD, ADHD, and other mental, emotional, and behavioral problems. Activity limitation occurred nearly twice as often among boys as girls reflecting, in part, the higher prevalence and more frequent diagnosis of certain conditions such as ADHD in boys than girls.

Conclusion: Parents more often reported activity limitations for school-age children than preschool children, and frequently selected conditions associated with learning, behavioral, and speech problems as a cause of activity limitation in school-age children.

Public Health Implication: The prominence of conditions related to learning and behavior as causes of activity limitation in children suggests the key role that schools play in identifying disabling emotional, behavioral, and learning disorders and the importance of coordinating educational and health services for children.

PDQ-1 and ABC as Autism Screeners

Authors: *W. Zahorodny, M. Brimacombe, V. Rodriguez, J. Vidal, M.Goldfarb*

Background: Though autism may be discerned in many affected children before age 3, clinical identification and intervention often do not occur until later. There is no widely-utilized autism screener for toddlers. The Autism Behavior Checklist (ABC), a 57 item, autism-specific, parent report questionnaire has been validated for children over age 4, but has not been studied as a screener for children age 12 to 36 months. The Psychological Development Questionnaire for Toddlers (PDQ-1) was developed as an 11 item parent report describing key features of psychological development occurring between 12 and 36 months. The objective of this investigation was to assess the reliability and validity of PDQ-1 and the ABC as autism screeners for toddlers.

Method: The psychological development of 180 children (12 months to 36 months) was assessed using the Psychological Development Questionnaire for Toddlers (PDQ-1), the Autism Behavior Checklist (ABC), and the Autism Diagnostic Interview, Revised (ADI-R). PDQ-1 and ABC scores representing psychological development in 41 subjects (toddlers) with autism were compared to PDQ-1 and ABC scores from 38 toddlers with developmental delay and 100 typically-developing subjects. A randomly selected (20%) sample of parents of autistic (n=8), developmentally delayed (n=8), and typical subjects (n=20) completed the PDQ-1 and ABC twice, at a one week interval. PDQ-1 and ABC scores of 41 subjects with autism were compared to independently-determined Autism Diagnostic Interview, Revised (ADI-R) scores (gold standard for autism diagnosis) for this group.

Result: Comparison of mean PDQ-1 and ABC scores showed a significant difference between groups (one way ANOVA, F test; P-value<0.001). PDQ-1 and ABC scores were significantly correlated (-0.869; P-value<0.001). Both PDQ-1 and ABC scores, respectively, were consistent over this period. Concordance of PDQ-1 score and ABC score with ADI-R total score, ADI-social score, and ADI-communication score at diagnostic threshold levels was 100%. Concordance of PDQ-1 score and ABC score with ADI-repetitive behavior score was 60% and 56%, respectively.

Conclusion: The PDQ-1 and ABC may be useful as autism screeners for children between 12 and 36 months. The brevity of the PDQ-1 and the ease with which it can be administered commend it as an autism screener for toddler-age children.

Periconceptional Dietary Intake of Choline and Betaine and Neural Tube Defects In Offspring

Authors: *G. Shaw, S. Carmichael, W. Yang, S. Selvin, D. Schaffer*

Background: For more than three decades, maternal nutritional factors have been implicated in the etiologies of neural tube defects (NTDs). Although periconceptional intake of folic acid has been identified as a successful preventive for some NTDs, other factors, including other nutrients are likely to contribute to the complex etiology of these birth defects. We investigated whether maternal periconceptional dietary intakes of choline and betaine influenced risk of having NTD-affected pregnancies. Choline and its metabolite betaine are methyl donors in the methylation of homocysteine to methionine and are utilized for the synthesis of cell membrane phospholipids.

Method: Data were derived from a case-control study of fetuses and infants with NTDs among 1989-91 California births. In-person interviews were conducted with mothers of 424 NTD cases (including fetuses and infants electively terminated, stillborn, or born alive) and with mothers of 440 nonmalformed controls within an average of 5 months from the term delivery date. A standard 100-item food frequency questionnaire was used to assess nutrient intake from diet.

Result: Periconceptional intakes of diets with choline or betaine were associated with reduced risks of NTD-affected pregnancies. Controlling for potential effects of maternal intake of supplemental folic acid, dietary folate, dietary methionine, and other covariates did not substantially influence risk estimates for choline but did attenuate those for betaine. NTD risk estimates were lowest among women whose diets were rich in both choline and methionine, as well as choline, betaine and methionine. The latter result, based on comparing women whose intakes were above the 75th percentile of intake on all three nutrients to those whose intakes were below the 25th percentile on all three nutrients, revealed a 79 percent decrease in risk (odds ratio=0.21, 95% confidence interval 0.05-0.93).

Conclusion: Fortification of the US food supply with folic acid is associated with a decreased prevalence of NTDs. However, a substantial population burden of these serious birth defects still remains. Our findings associated with other dietary components offer additional supporting clues toward understanding the complex etiology of NTDs.

Periconceptional Exposure To Oral Contraceptives and The Risk Of Neural Tube Defects

Authors: *S. Hernández-Díaz, M. Werler, C. Louik, A. Mitchell*

Background: Folic acid supplementation reduces the risk of neural tube defects (NTDs). We have previously found that various folic acid antagonists may increase the risk of NTDs, and that concomitant use of folic acid-containing multivitamins appeared to eliminate the increase in risk for some of them. Oral contraceptives have been associated with folate deficiency and some studies have suggested an association between OCs and NTDs. However, those studies did not consider the

role of folic acid supplementation. Therefore, our objective was to determine whether periconceptional exposure to OCs increases the risk of NTDs, and to take into account whether periconceptional multivitamin supplementation modifies that risk.

Method: Using data from the Slone Epidemiology Center Birth Defects Study, obtained between 1976 and 2001, we compared exposure to OCs after the last menstrual period for 1,323 infants with NTDs with data on 5,958 control infants with malformations not previously associated either with OCs or with vitamin supplementation. Mothers were interviewed within six months of delivery about demographic, reproductive, medical and behavioral factors, and medication use (including specific questions on OCs). We used logistic regression to estimate odds ratios (OR) and 95% confidence intervals (CI) and to adjust for region, interview year, maternal age, race, weight, education, and folic acid supplementation.

Result: Overall, 4.6% of cases and 2.6% of control women were exposed to OCs (OR=1.5; 95%CI: 1.1, 2.1). The OR was 1.6 (1.1-2.2) among OC users who had not used folic acid supplementation and 0.7 (0.2-2.4) among those who had used it, compared to users of none. However, the latter analyses were based on very small numbers. Use of contraceptive methods other than OCs was not associated with NTDs. Results were similar when we used infants without any malformation as controls.

Conclusion: These preliminary findings are consistent with a modest association between OCs and NTDs. Due to small number of women exposed to both folic acid and OCs after the last menstrual period, further data are needed to assess this potential interaction.

Public Health Implication: A lower risk of NTDs associated with concomitant use of OCs and folic acid supplementation would support the public health value of supplementing OCs with folic acid.

Physical and Psychosocial Health for Children with Spina Bifida

Authors: *K. Hauser, G. Watts, P. Rouhani, D. Wood, J. Frias*

Background: To understand the impact of the physical (PH) and mental/psychosocial (MH) health problems on the quality of life (QOL) of individuals with spina bifida (SB), a survey using standardized instruments was administered to a sample of these individuals living in Florida.

Method: We recruited a cohort between the ages of 5 and 30 years to participate in an hour long telephone survey. Its purpose was to identify secondary conditions and utilization of health care, educational, and developmental disability services and to gain a better understanding of QOL. Two questionnaires were developed, one for primary care givers (PCG) and the other for affected individuals. The PCG survey was used for those individuals between 5 and 16 years old or for older individuals who could not answer for themselves. QOL was assessed using the Child Health Questionnaire on the PCG survey and the SF-36®, Version 1 on the survey for individuals. Both instruments provided standardized summary measures of PH and MH.

Result: Questionnaires were completed by 124 individuals (90 PCG and 34 individuals). The majority of the cohort, 68%, was between 5 and 17 years old, 57% lived in an urban area, and 63% resided with both parents or both parents and siblings. In 84% of the cases, the SB was located in the lumbar and lumbar-sacral region and in the remaining 16%, in the thoracic region or higher. The most frequent secondary condition was hydrocephalus, present in 65% individuals, followed by urinary tract infections (UTI) and skin breakdown/ pressure sores, present in 55% and 40% of the individuals, respectively. Responses indicated that in 81% of the cohort the general health of the individual with SB was either good, very good, or excellent. While general health was good, the summary measure for PH was lower than the published norms for the two instruments. However, the summary measure for MH was comparable to the instruments' published norms.

Conclusion: The responses indicated that this cohort was perceived as being in good general health despite the fact that the majority had serious secondary conditions. Reported quality of life appears to relate more to MH than PH.

Public Health Implication: If our observation that mental health is more predictive of QOL than physical health is confirmed, the public health system should facilitate the study of mental health and function in persons with spina bifida and increase the availability of mental health services for this population.

Placental Glutathione-S-Transferase Pi Activity and Genotype In A Population of Hispanic Women

Authors: *T. Dodd-Butera, P. Quintana, S. Ingmanson, C. Shaputnic, M. Ramirez-Zetina, A. Batista, M. Sierra*

Background: Placental function is paramount to maintaining optimum conditions both in utero and for long term fetal development. Glutathione-S-transferases (GSTs) play a role in the placenta by protecting the fetus from toxicants and oxidative stress. A soluble form of GST, GST pi (GSTP1), accounts for a significant amount of placental GST enzyme activity. Previous studies indicate that the Ile105Val polymorphism in GSTP1 affects susceptibility to pathologic conditions of pregnancy such as preeclampsia and recurrent pregnancy loss. GSTP1 also detoxifies environmental carcinogens such as polyaromatic hydrocarbons (PAHs). This study investigates the relationship between placental levels of GST pi, placental GST pi enzyme activity, and maternal and placental GSTP1 and GSTM1 genotypes.

Method: Placental tissue, maternal blood samples were collected from 49 consenting obstetric patients from Tijuana, Baja California (BC), Mexico (maternal age mean 25.8, range 16 - 39 years). Placental GST pi levels were measured via Western blots. GST activity was measured against CDNB. Genetic polymorphisms in mother and placenta were assessed by PCR (GSTM1) and PCR-RFLP (GSTP1).

Result: Activity of placental supernatant against CDNB (substrate for GST pi) ranged from 21 - 623 nmol/min/ml, an almost 30-fold variability between subjects. Activity and levels of GSTPi were modestly correlated ($r = 0.359$, $p = 0.13$). No difference was found in placental GSTPi activity associated with the GSTP1 Ile105/Ile105 genotype vs. the Val105/Val105 genotype, although this had previously been reported for other tissues. An increased activity was however observed in placental supernatant from GSTP1 Ile105 positive mother/baby pairs that were concordant for GST mu (GSTM1) negative genotype vs. pairs with GSTM1 positive genotype, though numbers were very small (n=6 vs. n=31, $p = 0.024$).

Conclusion: Placental variability in levels and activity of the protective enzyme GST pi can be substantial between Hispanic women. Genetic variation at GSTP1 ile105val does not appear to explain variability in activity, in contrast to studies in other tissues such as lung.

Public Health Implication: Studies on nutritional and environmental factors affecting levels and activity of detoxifying enzymes in the placenta may help elucidate which pregnancies are more at risk from endogenous and environmental toxicants.

Predictors of Early Diagnosis In Autism Spectrum Disorders

Authors: *L. Arnstein, J. Charles, J. Nicholas, L. King, and R. Brown*

Background: Early intervention is believed to be critical in effecting positive outcome among young children with autism spectrum disorders. Access to early intervention is promoted when children are identified early.

Method: A cohort of children (n=62) with a diagnosis of autism receiving services in a health sciences center served as participants in this investigation. Simple linear regression was used to test the potential association of age of diagnosis with two sets of variables: those associated with a more typical autism profile and those associated with access to healthcare.

Result: Data revealed that the presence of early language delay, lower scores on cognitive tests, and greater severity of autism were associated with earlier age of diagnosis. Intelligence alone best predicted age of diagnosis (i.e. accounted for the greatest percentage of variance in comparison to other models tested).

Conclusion: Results suggest that children with specific neurobehavioral profiles may be more likely to be identified at an early age. Importantly, variables associated with access to healthcare were not associated with age of diagnosis in this cohort.

Public Health Implication: Results suggest that children without significant delays may be more likely to be missed during the critical early intervention period. Increased focus may need to be directed towards identifying these children.

Preference Ratings for Health and Disability States Are Different For People With Disabilities Compared To The General Population

Authors: *E. Andresen, A. Recktenwald, K. Gillespie, S. Boslaugh*

Background: Preference or utility values about health states are used in economic analyses that consider resource allocations for various treatment options, and describe economic implications among competing health care needs. The average ratings of people from the general population are derived from direct elicitation using "scenarios" to describe potential health states, valued from 0 (representing death) to 1.0 (representing maximal health). In theory and some previous tests, people with experience of a condition might provide an evaluation that is higher (closer to 1.0) than those without such intimate knowledge.

Method: We tested this hypothesis by providing descriptive scenarios of various mobility impairment states and health status to persons selected from the general population by random-digit dialing (RDD), and people with mobility impairments (PWD). 42 RDD and 46 PWD completed 3 varieties of preference-rating exercises based on an in-person computer program with visual prompts: standard gamble (SG), time trade off (TTO), and a visual analogue (VA) scale. Among 6 scenarios (e.g., a person with spinal cord injury [SCI] who uses an electric chair) we also randomly varied descriptors of health status (e.g., excellent versus good health). We also used a standard scenario based on blindness as a "control" measure.

Result: Among all 6 mobility scenarios, PWD gave preference ratings that were .06 (VA method) to .10 (SG and TTO methods) higher than RDD participants. Some scenario values were strikingly different. For example, in a scenario describing an employed person with SCI using an electric wheelchair, somewhat limited social life, and personal care needs, PWD gave a SG value of 0.89 compared to 0.27 by people recruited by RDD, or 0.63 closer to the maximum preference rating of 1.0. Variations in health status for scenarios were not consistently different by group. Somewhat surprisingly, the preference difference was not limited to mobility scenarios, but also was apparent in scenarios describing blindness.

Conclusion: We conclude that evaluations of disability states are substantially higher among PWD than the general population.

Public Health Implication: Applications of population values for resource allocations may need to consider differences based on PWD, especially for decisions that affect them directly.

Prenatal and Birth History Related Risk Factors in a Cohort of Autistic Patients

Authors: *M. Brimacombe, X. Ming, M. Lamendola*

Background: An epidemiologic cohort study was conducted to identify specific prenatal & birth history related risk factors associated with autism. The cohort consisted of one hundred and forty-four autistic patients referred to the Autism Clinic at the New Jersey Medical School – UMDNJ over a two-year period.

Method: As part of patient intake, parents completed a detailed survey consisting partly of questions regarding prenatal and birth history. This information was reviewed and clinical information validated by the supervising clinician. Frequencies of various birth and prenatal difficulties were assessed and compared to national and New Jersey levels.

Result: Significantly higher rates were found for the autism cohort versus reported national levels for the following risk factors; prematurity (16.7% to 11.6%, P=.044), vaginal bleeding (16.7% to 6.6%, P=.001), prolonged labor (7.6% to .78%, P=.001), caesarian delivery (29.9% to 22.9%, P=.032), multiple delivery (9.7% to 3.1%, P=.001) and diabetes (6.3% to 2.9%, P=.025). Comparison with NJ rates were similar.

Conclusion: These results support underlying genetic and environmental causes of autism and show lower levels of birth optimality in mothers of autistic children.

Prevalence of 2-Methylbutyrl-COA Dehydrogenase Deficiency (MBADD) Identified by Newborn Screening in the Hmong-American Population of Wisconsin

Authors: *M. Durkin, S. van Calcar, H. Lindh, G. Hoffman, W. Rhead, J. Wolff*

Background: 2-Methylbutyrl-CoA Dehydrogenase Deficiency (MBADD) is a rare inborn error of isoleucine metabolism first identified in 1999 that may lead to neurodevelopmental impairments. Using tandem mass spectrometry, MBADD can be detected by state-mandated newborn screening programs. During the initial year of implementation of tandem mass spectrometry in Minnesota and Wisconsin (2001), 8 cases of MBADD were detected, all in infants of Hmong decent. Although procedures are in place for routine newborn screening for MBADD, neither the natural history of this deficiency nor the utility of early l-carnitine treatment and dietary

intervention are known. The purposes of this study were to estimate the prevalence of MBADD based on newborn screening results, and to consider implications for newborn screening policies and public health practice.

Method: Anonymous data from the first 32 months (4/2001-12/2003) in which tandem mass spectrometry was used for newborn screening in Wisconsin were reviewed, and the number of infants screening positive for MBADD were identified by ethnicity and divided by the corresponding number of live births

Result: 16 infants screened positive for MBADD during the study period, among an estimated 184,032 infants screened, corresponding to a prevalence of 1/11,502 live births. All 16 cases were infants of Hmong decent. According to vital records for the same period, approximately 3,795 infants of Hmong/Laotian decent were born in the State of Wisconsin during this period. Thus, the estimated prevalence of MBADD in the Hmong-American sub-population of Wisconsin is 1/238 (95% confidence interval 1/159, 1/476).

Conclusion: The prevalence of MBADD is clearly elevated in infants of Hmong decent in Wisconsin.

Public Health Implication: Further studies are needed to evaluate the developmental outcomes of MBADD, as well as the need for newborn screening for this disorder and the need for, barriers to and efficacy of early treatment and dietary restriction.

Prevalence of Multivitamin Use - New Data From The Pregnancy Risk Assessment Monitoring System (PRAMS), 2000

Authors: *L. Williams, N. Whitehead, B. Morrow, A. Lansky*

Background: Increased folic acid consumption before conception and in early pregnancy reduces the incidence of neural tube defects and can also reduce the incidence of certain congenital heart defects. Most generally available multivitamins contain 400µg of folic acid, which is the recommended daily dose for women of childbearing age. In 2000, PRAMS began asking women if they took a multivitamin in the month before they became pregnant.

Method: PRAMS employs a mixed-mode data collection methodology; as many as three self-administered surveys are mailed to mothers in the sample, and nonresponders receive a follow up telephone interview. This analysis includes data from 19 states that collected data on year 2000 births and achieved weighted response rates of at least 70%. To assess folic acid consumption, multivitamin use was measured (i.e., taking a multivitamin four or more times per week during the month before pregnancy). Percentages and 95% confidence intervals were calculated using SUDAAN to account for complex survey design. The chi square test was used to identify statistically significant associations between the sociodemographic variables and multivitamin use for each state.

Result: Across the 19 states, 25.0%–40.7% of women reported taking a multivitamin four or more times per week in the month before pregnancy. In all states, the prevalence of multivitamin use increased with increasing maternal age, women with >12 years of education were significantly more likely than women with <12 years to use multivitamins, and women receiving Medicaid were significantly less likely than those not receiving Medicaid to report multivitamin use. In 14 states, Black women were significantly less likely to report multivitamin use than women in the White /Other category. Non-Hispanic women were more likely than Hispanic women to report multivitamin use in 10 states.

Conclusion: Certain sociodemographic groups of women were less likely to engage in multivitamin use. PRAMS data indicate that all 19 states were well below the Healthy People 2010 objective for folic acid consumption, as measured by multivitamin use.

Public Health Implication: These data can be used to tailor the development of state-based programs, for example, education initiatives and services for women at highest risk in each state. By obtaining more years of data on folic acid consumption and by continuing the monitoring of the prevalence and sociodemographic characteristics of women reporting this behavior, states can help clarify patterns and direct appropriate prevention strategies.

Prevention/Intervention Programs For Fetal Alcohol Syndrome (FAS) In South Africa: What Have We Learnt So Far?

Authors: *S. Schön, J. Rosenthal, M. Nero, D. Viljoen*

Background: FAS is the single most common birth defect and preventable cause of mental retardation in South Africa (SA). A research project on the epidemiology of FAS in De Aar, Northern Cape Province

SA, found the prevalence to be 103/1000 school-entry children in this community. This is the highest incidence reported thus far in SA. An intervention program for the prevention of FAS was implemented in De Aar in March 2003 in an attempt to address this public health problem.

Method: The incidence of FAS in 9 month old babies in a 12 month birth cohort was determined through clinical appraisal, neurodevelopmental assessment and maternal interviews starting from March 2003. Of 30 mothers who have a baby identified with FAS, 12 were interviewed using a previously tested and standardized interview schedule. Seventeen items assessing maternal drinking behaviour and reproductive patterns have been analyzed.

Result: The average maternal age was 32 years. Of the 12 women interviewed, 11 (91,6%) reported heavy drinking and smoking during pregnancy. Two (16,6%) women were not using contraception after the index pregnancy due to side-effects and 9 (75%) pregnancies were unplanned. The average gestational age at first presentation to antenatal clinics was 16 weeks with 10/12 mothers (83,3%) attending only after 12 weeks. Eleven mothers (91,6%) reportedly had previous knowledge of FAS.

Conclusion: Evidently, education efforts thus far have had little effect on drinking behaviour.The results identified a lack of family planning, failure to commence antenatal care during the first trimester of pregnancy, and failure to change behaviour despite a knowledge of FAS.

Public Health Implication: Identification of traits and behaviour of mothers of children with FAS can guide appropriate prevention/intervention initiatives in at-risk communities. Primary prevention efforts for FAS rely on family planning, antenatal care services and community education. Services are available in De Aar but seem to be underutilized. Further investigation should be considered to assess the delivery of family planning, antenatal and perinatal services in order to identify the training and education needs of health care workers and the community.

Program for Amputee Life Skills (PALS)

Authors: *E. MacKenzie, S. Wegener, S. Weir, P. Ephraim, P. Rossbach, and P. Isenberg*

Background: Each year 52 per 100,000 Americans are hospitalized for an amputation and an estimated 1.2 million Americans are currently living with the loss of a limb. Pain, psychological distress, reduced function and disability are common conditions following limb loss and are related to reduced quality of life. Depression, anxiety, and pain are significant problems for community dwelling persons with limb loss. Traditionally, interventions for disabling impairments and related secondary conditions focus on standard medical treatments such as medication, surgery or rehabilitative therapies. However, group and individually based self-management (SM) interventions have been found to be effective in reducing the secondary conditions and disability associated with selected chronic conditions. The present study is designed to test the efficacy of a community-based SM intervention for persons with limb loss.

Method: The study utilizes a randomized control design with fifty groups of 10-12 persons randomly assigned to either a control or intervention group. Groups of participants will be recruited from the already exisitng national network of community-based peer support groups developed by the Amputee Coalition of America. Individuals in the intervention group will participate in a 10 week SM intervention. Control group participants will attend regurarly scheduled amputee support group meetings. Assessments will be conducted at baseline, treatment completion, 3 and 6 months. The primary outcome measures are pain, anxiety, depression, and positive mood. Secondary outcome measures are restrictions in activities and participation and health related quality of life.

Result: The national clinical trial will begin in Fall 2004. The PALS intervention structure, process and content will be presented. Data from a single group pilot study regarding intervention feasibility and a pre-and post-comparison on intervention outcomes will be presented.

Conclusion: Establishing the efficacy of community-based SM interventions for person with limb loss has the potential to reduce secondary conditions and improve the health and well-being among persons with limb loss.

Promoting Health and Wellness for Persons with Disabilities In 16 States

Authors: *R. Carlin, V. Kurlantzick*

Background: In 2002 AAHD and 16 state health departments were awarded cooperative agreement grants from Disability and Health Team of the National Center on Birth Defects and Disabilities branch of the

CDC to "determine and develop the training, research and program implementation needs to assist in building health promotion and wellness programs at the state levels which address Healthy People 2010 focus area of Disability and Secondary Conditions." The 16 states, AK, CA, IA, IL, MA, MT, NJ, NM, NY, NC, OR, RI, SC, VT,VA, and WA, developed programs to improve state surveillance activities, conduct health promotion interventions, and facilitate partnerships between state- and research-or service based agencies. AAHD is disseminating current scientific and programmatic information through its web-site (www.aahd.us), list serves, professional meetings, and fact sheets to the states. This poster will showcase examples of programs conducted in each of the states.

Method: Three methods used by states are: surveillance to demonstrate need and measure efficacy, environmental interventions to improve access to health care and preventive services, and behavioral interventions. Interventions are implemented with research components using pre-post or case-control designs for formal evaluation. For example, Oregon's health promotion workshops are evaluated using instruments pre- and post-intervention to measure changes in the client's knowledge, perceptions, or behaviors. South Carolina's nutrition workshops for people with developmental disabilities are evaluated by matching cases with controls who do not have developmental disabilities.

Result: Sizes of populations with disabilities and disparities in access to health promotion services have been documented. Access to services has improved, and many individuals with disabilities have received training in nutrition, physical activity, self-advocacy, and issues surrounding depression, violence, and substance abuse.

Conclusion: Programs to measure and improve health and wellness of people with disabilities are successful in a variety of forms in achieving multiple and diverse specific goals.

Public Health Implication: Programs from each of the states can serve as replicable models of ways to prevent secondary conditions and improve quality of life for people with disabilities.

Public Health Informatics Best Practices: A Practical Approach to Data Modeling and Database Design

Author: *T. Savel*

Background: In many cases, public health surveillance system databases that are quickly built to solve a short-term solution end up being used for a long period of time. Problems often occur with these systems, including performance and data corruption issues. One solution to these problems is the use of a well-defined and structured design process, prior to the actual implementation of the database.

Method: Once all data sources have been gathered, a proper Entity-Relationship (ER) model should be developed. This conceptual diagram (schema) displays the fundamental information about the entities (representing "objects" in the real word), as well as how they "relate" to each other. As a rule of thumb, nouns define entities and verbs define relationships. The relationships are usually defined as either 1-to-1, 1-to-many, or many-to-many. Once the ER diagram is completed, creating the tables in the relational database is a straightforward conversion process.

Result: Through the use of this data modeling technique, the resulting relational database generated will be normalized. The well-normalized database will be very efficient, stable, and scalable. Specifically, the database will develop minimal data redundancy, loss, or corruption as changes to the data occur.

Conclusion: Although the development of an ER diagram prior to the creation of a relational database requires significant time and effort, it is minimal compared to the time and effort required to repair a poorly-designed, slow and corrupt database.

Public Health Implication: Given the value of public health data, and the significant time that surveillance systems can be in use, it is crucial that the systems' developers create well-normalized databases, thus preventing possible future performance issues, and more importantly possible data corruption or loss.

Recurrence Prevention Campaign: Social Marketing Efforts and Progress

Author: *A. Griffen*

Background: The Recurrence Prevention Campaign is a three-year national campaign which began in September 2002 to educate women at increased risk for neural tube defect (NTD)-affected pregnancies (specifically women who have a child with spina bifida, have spina bifida themselves, or have had an NTD-affected pregnancy) and their health care providers about the importance of increasing folic acid consumption by prescription prior to future pregnancies.

Method: The Campaign works on a national level with a focus in three states with traditionally higher rates of spina bifida: AL, NC and TX. The Campaign works with SBAA chapters, spina bifida clinics, and partners on the National Council on Folic Acid and the private sector. Social marketing approaches guide outreach to local libraries, health departments, medical societies, banks and grocery stores; media outreach in target states; and development of a folic acid counseling tutorial, Got a Minute? (March 2003), based on formative audience research.

Result: SBAA's National Survey of the Spina Bifida Community examined provider counseling and awareness among women at increased risk for NTDs (t1 February 2003, N=420, t2 August 2003, N=267). Data from the next survey (March 2004) are available at this presentation. Survey data were analyzed for the country as a whole due to low Ns in campaign target states. The survey found increased levels of folic acid counseling by providers (t1 59%, t2 63%), consumption (t1 33% everyday, 15% < 7 days/wk; t2 36% everyday, 18% <7days/wk), perception of folic acid effectiveness (t1 15% very effective, t2 19% very effective) and awareness of how much folic acid to take when planning a pregnancy (t1 32%, t2 39%). Process data show that folic acid is being mentioned to women and providers 57% more often by spina bifida clinics and local SBAA chapters. Media advocacy efforts to date have resulted in TV, radio and print placements reaching more than 6 million people.

Conclusion: Sustainable awareness efforts are needed as most women at increased risk for NTDs are not aware of their need for prescription folic acid and are often not counseled by a health care professional.

Public Health Implication: At a cost of a few pennies a day, folic acid needs to be seen as a national prevention strategy to reduce the risk of future spina bifida pregnancies. Over $200 million is spent on annual medical costs for people living with spina bifida. A top down approach of further professional education must be matched with a bottom up approach of arming women at risk for recurrence with the information they need, along with sustaining behavioral change efforts for women.

Results of Neural Tube Defects Case Ascertainment Process Combining Vital Records Datasets and Birth Defects Surveillance Data, For Years 1996 Through 2001, In Puerto Rico

Authors: *H. Garcia, J. Mulinare, E. Correa, D. Valencia*

Background: The Birth Defects Surveillance System (BDSS), in it's effort to ascertain all cases with neural tube defects (NTD) in Puerto Rico, has developed an active case ascertainment in which 5 field abstractors visit 100% of the hospitals at regular intervals where births occur. In addition, the BDSS has collaborated with the Puerto Rico Vital Records Office to identify potential NTD cases. Cases with an NTD diagnosis are identified from Vital Records datasets including live births, fetal deaths and death certificates for years 1996 to 2001. Using these two sources, we found that the prevalence of NTD in Puerto Rico has declined 58% from 1996 to 2001.

Method: Data from the Vital Records Office were decoded from an ASCII file using a layout and syntax designed in SPSS and then linked to the BDSS data. 198 cases with NTD's were considered from the vital records datasets and 405 from BDSS. A match with the BDSS data was done by using delivery date, child and parent names, and social security number.

Result: For the years 1996 to 2001, 93%(405/435) of all NTD cases were found through the existing hospital based surveillance. An additional 7%(30/435) of cases were found from vital records. Of 198 potential cases found in the vital records datasets with possible NTD diagnosis, 53%(110) were matched with BDSS data. From among the remaining 88 cases, 15%(30) were confirmed as NTD cases in hospital records, 5%(10) did not meet the NTD case definition and 27%(49) were pending hospital record review by case abstractors. Surveillance case detection for NTD cases had a high sensitivity of 93%(405/435) and predictive positive value of 98%(405/415)

Conclusion: Very high ascertainment (93%) of NTD cases was achieved through surveillance. Although it proved to be an effective source for NTD abstraction, vital records contributed with abstracting an additional 7% of NTD cases, not found through active hospital based surveillance.

Public Health Implication: In this study we show that although most of the NTD cases have been ascertained through epidemiological surveillance, we shall also rely on vital records as an additional source of NTD ascertainment in Puerto Rico.

SAS Output Delivery System: Part of an Integrated Project Management Approach

Author: *C.J. Alverson*

Background: A major challenge in public health research is the tension between organizing research activities and producing timely responses to research questions. The tendency of rapid or short term responses to research questions is to compute now, report rapidly, and then to move on. The ongoing nature of public health research makes it difficult to employ project archiving, and makes research continuity challenging.

Method: We will present and demonstrate a method for project management that centers around the management of information in a single project directory. We will employ emerging technologies that allow the organization and linking of project information. This method is integral to the research process, and adds no additional operational costs, yet reaps additional benefits.
Components of the model include: a complete, indexed set of documentation files; a complete, indexed set of data files; a complete, indexed set of data management and statistical programs and browse-able sets of statistical results and displays. The key application in enabling this model is a combination of web editing tools and SAS ODS.
SAS ODS produces permanent output in the form of HTML and JPG files, in a browse-able format. SAS ODS output can be easily viewed with any browser. SAS is not required to view these results. SAS ODS output can be easily and efficiently updated or revised with minimal effort. SAS ODS output consists of HTML and JPG files, and may be easily incorporated into other types of documents.

Result: The model, when properly employed, ensures that all of the documentation, data, programming, results and reports are available for writing, reassessment, clarification, recovery or audit. Effective use of the method fosters research team interactivity. Access to results is facilitated over multiple locations, using existing technology. Project materials are documented and archived on an ongoing basis in a transparent manner. Statistical results and displays are easily accessed and edited. The research team will need at a minimum a member who is proficient in SAS and statistical methodology. The method does not require any additional network or access technology.

Conclusion: Use of this method can enhance project documentation and continuity with minimal additional operational cost. When used consistently by a research team over multiple projects, key approaches and methods can be easily replicated and recalled for repeated use. Delays in publication can be minimized when project results are easily organized and accessible. The impact of team member turnover and new member training is minimized by use of project directories to facilitate training. The usual difficulties in viewing and using statistical results and displays by non-statisticians is minimized by ODS output, which is easily viewed and accessible without using SAS.

Public Health Implication: Use of this method may enhance the efficiency and productivity of public health research teams.

Satisfaction with Service Use By Families with a Child with Autism

Authors: *K. Thomas, J. Morrissey, A. Brewster*

Background: This presentation brings a services research perspective to understanding the structure, use and expenditures for the care and treatment of autism. Autism is a disorder that affects a person's ability to communicate and form relationships with others. The prevalence of autism in the population appears to be rising dramatically which has lead to growing federal and public interest. At this point, not much is known about families and the breadth and mix of their service use.

Method: This presentation presents findings from a survey conducted in the winter of 2003-4 of approximately 300 families in North Carolina with a child, 8 years old or younger, with autism. The presentation presents descriptive statistics and logit regressions.

Result: Findings from this survey will provide basic information about how families currently use the multiple treatments now available for autism, including behavioral, educational, and medical treatments, as well as complementary and alternative treatments. Analyses describe which treatments are utilized, by whom, and in what combinations. The study describes sources of

payment for care, family stress, coping, satisfaction and concerns with care. In particular, this presentation focuses on family satisfaction with service use. It identifies those services that families most often find useful and those that many families try and then stop using. Logit regressions describe child and family characteristics associated with satisfaction with each preferred service, as well as those associated with service termination.

Conclusion: Findings from this study will highlight any differences between services families find useful and those most consistent with effective treatment approaches. Family concerns with the system of care for autism may shed light on any discrepancies here and identify areas for future research.

Public Health Implication: This work can inform clinical trials and future demonstration projects.

Science Ambassador Program

Authors: *H. Carter, A. Nair, C. Prue*

Background: NCBDDD has well-documented scientific issues that fall into content areas required by the National Science Education Standards and could provide relevant educational opportunities for teachers and students. While NCBDDD has the scientific expertise, teachers have the educational training to develop effective lesson plans and activities that meet national and state standards which students are tested on regularly and for which teachers are held accountable. To provide a bridge between NCBDDD scientists and science teachers, NCBDDD has developed the Science Ambassador Program. In this program, NCBDDD scientists work with middle and high school science teachers to educate them about public health scientific issues and develop effective lesson plans which are then published on a web portal that is used by science teachers around the state and country.

Method: Teachers learn about a variety of different public health topics during an intensive workshop led by NCBDDD scientists. Participating teachers use this knowledge to write science lesson plans based on the workshop that meet national standards and are available nationally through Georgia's Department of Education Georgia Learning Connections (GLC) website. Every aspect of the program has been thoroughly evaluated using surveys, informal interviews, classroom observations, and informal email correspondence.

Result: A total of ten teachers participated in the first program in June 2003. Two teachers completed all three lesson plans and seven teachers have submitted one or two lesson plans for review. One teacher did not complete the program. By June 2004, approximately 10 lesson plans will be published on the widely used GLC website.

Conclusion: The first year of this pilot project has shown encouraging results. Quantitative and qualitative evaluations have shown that teachers were very excited to work with CDC and understand more clearly the science behind public health. Students have also shown an avid interest in public health issues and were actively engaged throughout the science lesson. From CDC's perspective, the published lesson plans have been worth the investment of time and energy involved in ensuring a high quality product.

Public Health Implication: The Science Ambassador Program is an example of a creative partnership which has used a web portal tool developed by Georgia's Department of Education to disseminate well-developed science lesson plans on various public health issues. The science that underpins public health practice showcases science concepts to students in a new and relevant way. Additionally, students have the chance to learn about public health at a much earlier age and potentially pique their interest in public health as a career.

Screening for High-Functioning Autism Spectrum Disorders In The Schools

Authors: *L. Miller, A. Ratchford, S. Hepburn, C. Robinson, C. DiGuiseppi, S. Rosenberg, K. Baldwin*

Background: Children with high-functioning Autism Spectrum Disorders (ASD) are likely to be missed by current school-based assessment procedures and thus are not identified until well into the school years. The delay in diagnosis adversely affects the child's access to appropriate interventions and educational modifications. The Autism Spectrum Screening Questionnaire (ASSQ), a teacher report measure, is a validated method of screening and has been shown to be very helpful for identifying children at risk for ASD within school settings. This tool, however, is too time-consuming and expensive to screen a large population of children as it requires 10-15 minutes per child to complete. There is a need to develop a quick, reliable method for identifying children who need further assessment for a possible ASD. The Nomination

Strategy is a method that has been shown to be both cost-effective and accurate for screening school-aged children with a variety of internalizing disorders. This method requires that a teacher nominate two children who best fit a list of descriptions (in order of best fit) of a particular disorder. Using the nomination concept, the investigators developed nomination criteria specific to ASD. The current project will compare the Nomination Strategy with the ASSQ to assess its effectiveness for use in school settings.

Method: This project will include a sample of up to 80 teachers in 80 classrooms, which will enable the screening of approximately 2400 children. The teachers will complete the ASSQ and the Nomination Strategy in random order with one-week between each administration. The scores on the ASSQ in each classroom will be compared to the nominations, in order to determine if the nomination process is as accurate as the longer questionnaire in identifying children with high-functioning ASD.

Result: Pending.

Conclusion: Pending.

Public Health Implication: The Nomination Strategy may prove to be an effective way of quickly screening children in general education classrooms to identify those who possibly have high-functioning ASD. If proven effective, the Nomination Strategy could be used for future epidemiologic studies or for the validation of an ASD surveillance program.

Seasonality and Excess Incidence in MACDP

Authors: *A. Correa, C. Alverson, C. Siffel*

Background: A key idea in birth defect surveillance is the detection of statistically significant excesses in incidence. Trend and seasonal variation must be considered in the longitudinal surveillance of birth defect incidence.In particular, there is some division and controversy regarding the role played by seasonal forces in driving birth defect incidence. The Metropolitan Atlanta Congenital Defects Prevention (MACDP) study provides fertile ground for the discussion and demonstration of current techniques for detecting seasonal variation and excess incidence of birth defects.

Method: We will demonstrate a variety of techniques to selected birth defect groups, including Hewitt methodology (for detecting excess incidence) and Elwood methodology (for detecting sinusoidal seasonal variation). We will also employ some novel techniques in graphically displaying the results of such analyses.

Result: Preliminary analyses via Hewitt suggests that there are significant cycles of excess birth defects for some birth defect categories. Preliminary analyses via Elwood does not detect any sinusoidal periodicity in MACDP. We will expand upon and refine these results.

Conclusion: The presence or absence of seasonal variation in MACDP birth defect rates varies with the definition of seasonal variation and with specific birth defect categories.

Public Health Implication: An understanding of seasonal variation is essential as a part of understanding the pattern of incidence of birth defects. The detection of excess birth defect incidence is a key to effective birth defect surveillance.

Smoking Status and Quality of Life: A Longitudinal Study Among Adults with Disabilities

Authors: *M. Mitra, N. Wilber*

Background: Current research suggests that people with disabilities are more likely to use tobacco,1 less likely to quit,1 and less likely to be screened for tobacco use. 2 However, little is known about the impact of changes in smoking status on the health-related quality of life (HRQL) of people with disabilities. The primary objective of this paper is to examine the association between changes in HRQL and smoking status over time among people with disabilities.

Method: The study data were derived from the Massachusetts Survey of Secondary Conditions, a three-phased longitudinal survey of 656 independently-living adults with disabilities. The main outcome measure was HRQL as measured by an enabled version of the Medical Outcomes Study Short Form-36 (SF-36).

Result: Current smokers and those who began smoking during follow-up had significantly poorer HRQL compared with non-smokers with disabilities. Longitudinal analysis suggests that controlling for age, gender, race/ethnicity, education, and activities of daily living, changes in HRQL scores over time were associated with changes in smoking status. Compared

to smokers, those who quit smoking during follow-up experienced a significant improvement in mean SF-36 scores over time for the dimensions of mental health, energy and vitality, and general health.

Conclusion: Results suggest a significant association between smoking status and HRQL among people with disabilities. Respondents who smoked and those who began smoking were more likely to report poorer HRQL than those who had not smoked during the period of the survey. In addition longitudinal changes in smoking status were associated with changes in HRQL.

Public Health Implication: Findings from this study highlight a strong need to inform public health programs, people with disabilities and health care providers about the association between tobacco use cessation and improved health-related quality of life among people with disabilities.

Spanish-Language Folic Acid Media Campaign - Increasing Knowledge and Changing Behavior Among Hispanic Women of Childbearing Age

Authors: *A. Flores, H. Carter, E. Fassett, C. Prue*

Background: Each year in the United States about 3,000 pregnancies are affected by neural tube defects (NTD's). Research shows that 50-70% of these defects could be prevented with adequate consumption of folic acid prior to and during early pregnancy. Hispanic women have been shown to have an elevated risk of NTDs and lower levels of awareness and knowledge about the benefits of folic acid. In September 2001, an intensive Spanish-language campaign (SFACES) targeting Hispanic women was launched to increase levels of folic acid knowledge, awareness, and consumption in this population by utilizing a combination of paid media efforts and interpersonal communication efforts at the local level by lay health workers, or promotoras.

Method: Intervention activities were conducted in two intervention markets, San Antonio TX, and Miami FL, during 2001/2002 and 2002/2003. Airtime was purchased to broadcast a CDC-produced Spanish-language PSA and local community outreach was conducted. The paid media campaign ran from September 2001 through December 2001, and from November 2002 through January 2003. Telephone surveys were conducted in the two intervention markets and six comparison markets with Hispanic women of childbearing age.

Result: Over the two campaign periods, results indicate an increase in folic acid awareness, knowledge, and consumption among women in the intervention markets as compared to women in comparison cities.

Conclusion: The SFACES campaign represents the first time CDC has received funding to conduct a paid media campaign. Evaluation efforts have shown dramatic increases in the levels of awareness and knowledge among Hispanic women in the intervention markets, as well as steady increases in folic acid intake. The campaign is evidence that a combination of health communication efforts can help influence Hispanic women's folic acid awareness, knowledge and consumption.

Public Health Implication: More health communication efforts are needed to increase folic acid consumption. Hispanics have become the largest minority in the United States and traditionally have high birth rates. The need for folic acid educational interventions aimed at this population is critical since high risk and high birth rates can translate into a greater number of NTD-affected pregnancies and births. This will not only impact individuals and families on an emotional and financial level, but have large implications for areas such as insurance, medical care, and special education costs.

Spatial Analysis of Birth Defects In Atlanta

Authors: *C. Siffel, C. J. Alverson, A. Correa*

Background: Surveillance systems have been implemented to monitor temporal changes in the occurrence of birth defects to identify potential environmental teratogens. However, surveillance systems that allow for analysis of spatial variations in the occurrence of birth defects are limited. We aimed to evaluate the feasibility of using birth defects surveillance data and census data to identify spatial aggregation of high rates of birth defects in metropolitan Atlanta.

Method: We examined data from the Metropolitan Atlanta Congenital Defects Program (MACDP), a population-based surveillance program of birth defects among infants born to residents of five counties in metropolitan Atlanta. Infants with birth defects (cases) born during the period 1968 through 2000 were geocoded

by assigning longitude and latitude (x, y) coordinates to the mother's residence at the time of delivery. For this analysis, we included cases born in 1990 (n = 1,266) among 38,779 recorded live births. The geocoded database was linked with a digitalized map of the metropolitan Atlanta area. Using a geographic information systems (GIS) software package (ArcView), we aggregated cases of all birth defects by census tract for 368 census tracts and linked the geocoded dataset with the 1990 census by census tract (total infants = 29,444). Census-specific prevalence rates were computed based on the census infant age group estimate as a proxy of live births for census tracts. We used SaTScan, a statistical software, to scan for possible clusters of birth defects (increased relative risk, RR) based on the Poisson distribution.

Result: The overall prevalence of birth defects in the study area was 4.33 per 100 infants. Maps of all cases of birth defects by census tract showed an aggregation of high rates in small areas, with high rates identified for several census tracts. The scan statistics identified a possible cluster of birth defects in three census tracts adjacent to each other: RR = 3.7; p = 0.030.

Conclusion: Use of census data to derive estimates of census tract-specific denominators allows for exploration of possible clusters, but findings need to be interpreted with caution because such estimates could underestimate the true denominator. Further work is warranted to identify more robust denominators.

Public Health Implication: A GIS database of birth defects can be useful in evaluations of spatial variations of birth defects in a defined population.

Stay Well and Healthy! An In-Home Preventive Healthcare Program for Persons Aging with Developmental Disability

Authors: *J.E. Hahn, H.U.Aronow*

Background: Like the general population of older persons, the life expectancy has increased for persons with intellectual and developmental disabilities (I/DD). The number of older persons is expected to double or triple by the year 2039. Persons with I/DD face a number of health disparities including limited access to preventive health care services. Other barriers may include: physical obstacles to accessing care, higher incidence of case complexity, earlier onset of age-related conditions, little or no experience with developmental disability among primary care providers, and interaction of age-related conditions and lifelong disability. The purpose of this pilot study was to develop and test a program, based on a Comprehensive Geriatric Assessment (CGA) model, to prevent premature functional decline and to promote health among persons with I/DD aging in the community.

Method: Participants with I/DD ages 32 years and older were randomly assigned to one of two levels of intervention. All participants received an in-home multi-dimensional health risk appraisal (HRA) administered by a trained interviewer. Half of the sample was randomly assigned to see an Advanced Practice Nurse (APN) for an in-home CGA and follow-up program. The interventions targeted health and lifestyle issues and promoted self care.

Result: The sample included 201 participants with I/DD with an average age of 41 years; males made up 52% of the sample. High levels of health risks were identified (Mean = 7.6; range 1-20). At baseline, 23.4% reported "fair" or "poor" general health; 16.4% probable depression; 28.1% doing no regular exercise; 31% identified as obese (defined as a BMI of 30 or more); 35.0% having either no person or only one person to call on for help or talk about private matters; only 21% a high level of satisfaction with life; and only 16% all age appropriate health maintenance screening tests (based on age-appropriate suggested tests). Reduction of health risks was noted in a number of areas on follow-up. A sum of health strengths was significantly positively correlated with the total score on community integration and significantly negatively correlated with the depression total score.

Conclusion: Comprehensive, multidimensional health assessments yield problems consistent with other findings about the older population with and without disability. The findings suggest that the main outcomes improved with preventive intervention, that HRA is sensitive to change, and then these interventions should be tested in randomized field trials. Findings suggest that interventions that increase health strengths may affect indicators of quality of life.

Public Health Implication: Preventive interventions are feasible for trials in persons aging with I/DD and have broad applicability to other populations aging with disability.

Surveillance and Long-Term Follow-Up of Infants Identified with Tandem Mass Spectrometry (MS/MS) Detectable Disorders: Interim Progress Report of A Three-Year Cooperative Agreement with the Centers For Disease Control, Idaho, Iowa and Oregon

Authors: *J. Tuerck, T. Deihn, A. Spencer, A. Kenneson*

Background: The objective of this project is to develop long-term follow-up protocols and perform surveillance for infants identified through MS/MS to have urea cycle, fatty acid oxidation and organic acid disorders in order to evaluate the efficacy of early diagnosis and treatment for these conditions.

Method: An exhaustive review of the literature was undertaken for 31 disorders and clinical presentation, MS/MS profile, confirmatory testing and medical management were catalogued for each disorder. Other long-term data systems, i.e. PKU, childhood cancer and craniofacial disorders were reviewed. Data items and case definitions are being established for evaluation of long term morbidity, mortality and cost outcomes. A parent questionnaire is being developed to assess the impact of the infant's diagnosis on access to and burden of care.

Result: Data collection forms have been developed for all 31 disorders and are under review by the collaborative group. These tools will permit standardized collection of data from treatment centers and medical home providers. Systems analysts are building a relational normalized MS Access database that will permit uniform data entry, relevant data linkages and reports for data analysis. Database development is expected to be complete by fall of 2004 followed by field-testing in all three states in 2005.

Public Health Implication: Using standardized case definitions, data collection tools and a common database, it will be possible to collect long-term outcome data on infants and children identified with 31 MS/MS disorders in order to evaluate the efficacy of this screening technology. This database can be extended to include all disorders included in screening batteries and provide a model for long-term follow up in other states and territories.

Surveillance of Orofacial Clefts In Victoria, Australia From 1983 Through 2000: A Report Using The Victorian Birth Defects Register

Authors: *L. Vallino, M. Riley, J. Halliday*

Background: There are few reports of population-based birth defect registers to specifically study the epidemiology of orofacial clefting. This study investigated the distribution of cleft lip and/or cleft palate (CL±P, CP) and infant characteristics using data obtained from the Victorian Birth Defects Register (VBDR), a statewide population-based surveillance system in Victoria, Australia.

Method: Using data reported to the VBDR during 1983-2000, we determined prevalence rates for all cases of CL±P and CP from all pregnancy outcomes. Based on a structured classification scheme, cases were categorized as isolated CL±P and CP or CL±P and CP occurring with other birth defects (classified as sequences, chromosomal anomalies, non-chromosomal syndromes, single system defects, and multiple system defects). Cleft data were also collected for infant gender and plurality. These data are collected from multiple sources up until 15 years of age.

Result: The prevalence rate (per 10,000 pregnancies) of isolated clefts was 12.1 and 5.6 for clefts associated with other birth defects, rates that have remained stable for 18 years. CL±P was the most common type of cleft type found in isolated cases and CP in infants having other birth defects. In contrast to isolated cleft conditions, perinatal mortality was high among cases of clefts occurring with other birth defects (prv=447.2 vs. 21.3), most frequently among neonatal deaths in infants with multiple system defects. In both categories, terminations occurred most often in infants with CL±P, however, the rate was significantly lower in isolated cases than in cases having other birth (23.4 vs. 196.5) defects particularly in infants with multiple system defects and chromosomal anomalies. In both categories males were more likely than females to have CL±P and females to have a higher rate of CP. Unlike isolated clefts, babies from multiple births were more likely to have a cleft with other birth defects than singleton births.

Conclusion: This population-based study underscored the epidemiological differences between isolated CL±P and CP and CL±P and CP associated with other birth defects, findings that are often diluted in most studies of cleft.

Public Health Implication: Surveillance using population-based data and a structured scheme provides an accurate and complete characterization of cleft conditions for which there is a great need. These data will influence our understanding of the disorder and help direct research and health care allocation. Obtaining accurate unbiased prevalence rates can lead to determining and evaluating prevention programs and enhance genetic counseling.

Teaming Parents and Health Professionals To Optimize Early Detection

Authors: *G. Girolami, S. Campbell, M. Nelson, J. Sarwark, H. G. Gardner*

Background: Enhancing the quality of life for children with physical movement differences by offering a tool to educate parents about the benefits of early detection and intervention is an essential role of the practitioner. The Pathways Awareness Foundation can assist health care providers in attaining this goal.

Method: Pathways utilizes a self-produced brochure, "Assure the Best for your Baby's Physical Development", formerly known as "Is My Baby Okay?", in conjunction with low-cost distribution opportunities to inform parents and the medical community about the early signs of physical movement disorders. The Illinois Chapter of the American Academy of Pediatrics endorses the brochure, written by the Foundation's Medical Roundtable team of experts. Our Medical Roundtable consists of leading physicians, therapists, nurse practitioners and lay advisors, who are sensitive to the medical and emotional needs of infants and children with physical movement differences, including cerebral palsy, and their families and/or caregivers. The centerpiece of the brochure is a unique chart with an illustrated comparison of postural and movement milestones of typically developing infants, juxtaposed with illustrations of postures associated with atypical development. The brochure also allows parents to track their child's physical, play and speech development from three to fifteen months of age. Additional written text advises parents about the benefits of early detection and therapy, and our "parent answered" toll-free number is provided for questions and recommendations for additional resources.

Result: Over 1.7 million copies of the brochure, available in English, Spanish, French and Portuguese, have already been distributed nationally and internationally. Early Intervention offices in each state have received complimentary copies, and many currently use it to fulfill the Child Find obligation of IDEA. Collaboration with the Offices of the Governor of Illinois and the Mayor of Chicago permits versions of the brochure to be mailed to every parent of an infant born in the state of Illinois.

Conclusion: Education of pediatric health care professionals and parents regarding early detection and intervention can save precious time, permitting children with movement disorders to achieve a higher level of function and improved quality of life.

Public Health Implication: Early diagnosis is important to receive treatment that maximizes a child's abilities. As we spread the word about early intervention, more children will have the opportunity to achieve their full potential.

Texas Survey and Biologics Participation Rates In The NBDPS

Authors: *M. Voloudakis, M. Canfield, P. Langlois, A. Novoa, J. Dyer*

Background: As a partner in the National Birth Defects Prevention Study (NBDPS), the Texas Center for Birth Defects Research and Prevention (TCBDRP) administers a telephone survey and collection of biologics (buccal cell swabs) from participants in the study. Participation in such research is challenging due to questionnaires that are long and personal in nature (Eaker, et al., 1998). In addition, over 60% of NBDPS participants in Texas are Hispanic; a group with unique participation patterns due to response tendencies, instrument design, and population-related variables (McAvoy et al., 2000; Lange, 2002). Therefore, as an effort to understand factors associated with participation in Texas, a project was designed to describe and examine participation with both portions of the study.

Method: Descriptive analyses of self-report items on telephone surveys and buccal return rates were used to examine the demographic makeup of the cases and controls that were and were not successfully recruited. Subsequently, logistic regression was used to examine the impact of relevant variables on buccal return.

Result: On the survey, no differences were found in completion or refusal regarding case status or race, but mothers with a live birth were less likely to participate than those without. For buccal return, controls were less likely to return and more likely to overtly refuse

participation. Regarding race, Hispanics were less likely to return buccals, and more likely to passively refuse participation. An inverse relationship was found between Hispanic acculturation and buccal return. Regression analyses showed age (B = 0.23, SE B = 0.01, p = .02), income (B = 0.23, SE B = 0.10, p = .02), education (B = 0.14, SE B = 0.04, p = .01) all positively related, while acculturation (B = -0.28, SE B = 0.07, p = .01) and non-live birth (B = -0.47, SE B = 0.17, p = .01) negatively related to buccal return.

Conclusion: This research has identified areas where the TCBDRP can focus recruitment efforts to increase participation in such a manner that will accurately represent the potential participant population. Specifically, highly acculturated Hispanics, younger, and less educated individuals will be targeted, along with controls.

Public Health Implication: Even when research is directly relevant to a population, demographic factors can impact participation. In birth defects surveillance research where adequate representation of all possible risk factors is crucial, obtaining a representative sample of potential participants is of high importance. Current results suggest the first step in obtaining such a sample is identifying those groups which may be underrepresented. Subsequently, targeted recruitment efforts can be made to increase participation from those groups.

The Acquisition of Adult Social Roles Among Young Adults with Developmental Disabilities

Authors: *K. Van Naarden Braun, M. Yeargin-Allsopp, D. Lollar*

Background: As children with developmental disabilities reach young adulthood, supportive services such as rehabilitation, special educational, and specialized pediatric care often cease. The new social roles of young adulthood, coupled with the vulnerabilities created as a result of declining support systems, underscore the need to examine the consequences of developmental disabilities in young adulthood. This study tests the hypothesis that for young adults with developmental disabilities difficulties in attaining age-appropriate normative social roles are not inevitable consequences of their childhood impairment.

Method: Two datasets from the Centers for Disease Control and Prevention were used to test this hypothesis in a cohort of young adults with a history of developmental disabilities. Conducted from 1984 to 1990, the Metropolitan Atlanta Developmental Disabilities Study (MADDS) was the first United States, epidemiologic study of serious impairments (i.e. mental retardation, epilepsy, cerebral palsy, hearing impairment, and vision impairment). From 1997-2000, the MADDS-Follow-Up Study of Young Adults was conducted which followed a subset of these children into young adulthood (age 20-25 years). The MADDS FU Study consisted of an extensive interview that obtained information including: functional status, normative adult social roles (e.g. competitive employment, post-secondary education), and independence (e.g. living arrangements, marriage).

Result: The results of this study suggest that: 1) attainment of adult social roles varies by impairment type and severity, 2) activity limitations partially mediate the relationship between impairment and adult social roles, and 3) attending at least some post-secondary education increases the likelihood of attaining markers of adulthood.

Conclusion: Negative social outcomes central to adulthood are not inevitable consequences of childhood impairment. The variability in attaining these roles by impairment type and severity underscores the need to consider interventions specific to young adults' impairment characteristics. The findings from this study emphasize the importance of preventing or lessening the number of limitations in daily activities and increasing attendance in post-secondary schooling.

Public Health Implication: Intervention to reduce limitations in daily activities and the development of strategies to increase attendance in post-secondary education may increase the likelihood for young adults to acquire normative adult social roles.

The Amputee Coalition of America's National Peer Network: A Model For Improving Wellness In People with Disabilities

Authors: *P. Rossbach, P. Isenberg*

Background: Each year there are more than 185,000 amputation surgeries in the U.S. The Amputee Coalition of America's (ACA) National Peer Network (NPN) was created to provide training and technical assistance for amputee support groups and individuals interested in providing peer support. In a recent survey, ACA found

that 69% of the more than 200 amputee support groups in the U.S. have an established peer visitor program and that many referrals to support groups are a result of peer visits. The value of peer support in coping with limb loss has been demonstrated repeatedly by the ACA since the inception of the NPN.

Method: The standardized peer visitor training materials and certification process implemented by ACA in 2001 ensure consistency in knowledge and skills among those certified due to the strong evaluation component that has been incorporated. The one day peer visitor training seminar includes discussion, case studies, and role play related to the recovery process in amputation, depression and grief, and effective communication. Resource materials include fact sheets focused on health and wellness.

Result: Peer visitation is reported, by those with limb loss and their healthcare providers, to be one of the most significant interventions an amputee, someone facing an amputation, or the parents of a child born with a limb deficiency, can experience. Anecdotal reports and a recent survey of people who received a peer visit indicate satisfaction with the quality of the interaction and the usefulness of materials and information provided during the initial visit and follow-up contacts. The best indicator of the success of the NPN's peer visitation program may indeed be the number of people receiving a visit who later become peer visitors in order to "give back."

Conclusion: Peer visitation is an effective model for addressing the psychosocial and health needs of people with limb loss. Knowing how to effectively train peer visitors and implement peer visitor services to meet ACA's goal of ensuring that any new amputee who wants contact with a peer visitor is able to receive that support continues to be a problem.

Public Health Implication: Peer support is a valuable tool for teaching coping skills, providing targeted information, and encouraging people with limb loss to actively pursue healthy lifestyles. This model is replicable for individuals with other disabilities. ACA's National Peer Network (NPN) will maintain its role of certifying trainers and amputee peer visitors while offering training and technical assistance to national, regional, and local organizations in how to recruit and train peer visitors for people with other disabilities.

The Co-Occurrence of Autism and Birth Defects

Authors: *D. Schendel, R. Wines, C. Moore, T. Karapurkar*

Background: The co-occurrence of autism and birth defects may elucidate factors acting during fetal development to cause autism. Studies have described birth defects among children with autism, but not assessed the risk for autism given the presence of specific birth defects in a population-based sample.

Method: To achieve both goals, this study linked two surveillance programs: the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) and the Metropolitan Atlanta Congenital Defects Program (MACDP). The study population consisted of Atlanta 3-year survivors, 1986-1993 (N=293,294), identified by MACDP with major birth defects (N=9354) or by MADDSP with autism (n=617).

Result: Among children with autism, 6.6% had a birth defect (versus 3% in the general population), mainly CNS (1.6%), genitourinary defects (1.3%), Down syndrome (0.6%), and primarily among boys (sex ratio = 9:1; excluding genitourinary defects=7:1). Among children with birth defects, the prevalence of autism per 1000 children was 4.4 (versus 2-6 per 1000 in the general population), 19.6 among children with CNS defects, 3.1 among children with genitourinary defects, and 17.1 in children with Down syndrome.

Conclusion: Having a birth defect doubled the autism risk, but the specific defect distribution does not suggest a common etiologic mechanism leading to autism. Funding was provided through the US Department of Health and Human Services, Centers for Disease Control and Prevention.

The Developmental Genome Anatomy Project (DGAP): In Search of Genes Critical For Human Development

Authors: *H. Ferguson, G. Bruns, D. Donovan, R. Eisenman, J. Gusella, D. Harris, S. Herrick, A. Higgins, N. Leach, A. Ligon, H. Kim, W. Lu, R. Maas, S. Michaud, A. Michelson, Steven D. Moore, R. Peters, B. Quade, F. Quintero-Rivera, R. Williamson, C. Morton*

Background: The Developmental Genome Anatomy Project (DGAP, http://dgap.harvard.edu) is a collaborative effort to identify genes critical in human

development. Balanced, de novo chromosome rearrangements occur in about 1/2500 newborns. Approximately 6% of these individuals have an abnormal phenotype. It is presumed that in a proportion of these individual the abnormal phenotype is due to gene disruption and/or gene dysregulation at one or more breakpoints. Historically, such a presumption has been validated by the discovery of multiple disease genes.

Method: Subjects eligible for DGAP have balanced chromosome rearrangements in addition to congenital anomalies. Most rearrangements are de novo in origin, although some cases of familial rearrangements segregating with a specific abnormality have been ascertained. DGAP utilizes a high-throughput approach including expertise in (1) patient identification and sample collection, (2) fluorescence in situ hybridization (FISH)-based breakpoint localization, (3) breakpoint cloning and candidate gene identification, and (4) functional analysis in model organisms. Chromosomal breakpoints are mapped to identify causal relationships between the rearrangement, due to gene disruption and/or dysregulation, and the abnormal phenotype.

Result: Approximately 137 cases have been contributed in collaboration with clinicians, cytogeneticists and genetic counselors. Using this method, 71 breakpoints have been mapped using FISH techniques. Thirty-seven of these breakpoints are positioned on the human genome map within a single bacteria artificial chromosome (BAC) clone. Thirteen of these breakpoints directly disrupt a gene sequence and 11 have been cloned.

Conclusion: DGAP represents a successful effort in the identification of genes important to human development.

Public Health Implication: The short-range benefit to the affected individual is a better understanding of a previously undefined disorder and its etiology. An expressed source of frustration for affected individuals and/or their families is the lack of information available for these unique cases. The long-range benefit to society is the provision of essential insight into human development.

The Economic Gains From Preventing Neural Tube Defects Through Folic Acid Fortification In The United States

Authors: *S. Grosse, N. Waitzman, Patrick S. Romano, J. Tilford, J. Mulinare, L. Williams, J. Cordero*

Background: In 1996 the U.S. Food and Drug Administration (FDA) required food processors to begin adding 140 micrograms of folic acid to every 100 grams of enriched grain products, effective 1998. While analyses prior to the FDA ruling suggested a positive net benefit, this is the first assessment of the actual benefits of the regulation.

Method: We calculated estimates of lifetime direct and indirect costs associated with births with spina bifida or anencephaly based on information on hospitalizations, other medical costs, developmental services, special education, parental caregiving time costs, and foregone productivity of affected individuals resulting from premature death or disability. We multiplied estimated costs by the numbers of live births with spina bifida or anencephaly calculated to be prevented each year as a result of folic acid fortification since 1998, based on birth defects surveillance reports. We do not attempt to calculate costs associated with pregnancy losses resulting from neural tube defects or cases of vitamin B12 deficiency that might go undiagnosed as a result of folic acid fortification.

Result: The preliminary estimate of the extra lifetime cost of an infant born with spina bifida is $760,000, discounted at 3% per year. This includes almost $300,000 per infant in medical and other direct expenditures. For anencephaly, the discounted lifetime cost is $1,050,000, comprised of the lifetime value of labor market and household productivity for an average person. The number of live births with spina bifida prevented each year by fortification is probably 500 to 550, and the number of live births with anencephaly prevented each year is 60 to 70. Accordingly, we estimate that society likely saves between $450 million and $500 million in direct and indirect costs for each cohort of newborns as a result of folic acid fortification.

Conclusion: In comparison with the estimated cost of folic acid fortification of perhaps $10 million per year, the economic gains are overwhelming. Our net benefit figure exceeds by a large margin the figures estimated prior to fortification being mandated.

Public Health Implication: Folic acid fortification has proven to be a major public health success story, both in terms of numbers of healthy babies born and costs

averted. However, much remains to be done to eliminate folic acid-preventable NTDs and the net benefit of other interventions still needs to be determined. Future analyses will compare expected costs and benefits from interventions such as promotion of supplements containing folic acid.

The Effect of Unsatisfactory Specimens on Newborn Screening

Authors: *L. Kalman, S. Grosse, O. Devine, H. Hannon*

Background: Every state has a public health program to identify newborn babies with life-threatening or disabling conditions through laboratory testing of dried blood spots. Babies born with screened conditions must receive treatment in the first few weeks of life to avoid risk of death or disability. Because testing of an incorrectly collected dried blood spot specimen can give false negative results, patients with unsatisfactory specimens (unsats) must return to their provider for collection of a repeat specimen. The objective of this study is to estimate the delay associated with unsats and the probability of failure to obtain a valid specimen.

Method: Data were collected from newborn screening records in two states. We examined reasons for why specimens were unsats, the delay between collection of unsats and collection of repeat specimens, the age of the baby when results from a satisfactory specimen are reported, and the number and types of specimens per baby.

Result: Preliminary data from one state suggest that unsats significantly delay the age at which an infant receives valid newborn screening results (control: median age 12 days, unsat: median age 28 days). We also found that for a large percentage (34%) of patients with initial unsats a satisfactory repeat specimen could not be documented to have been received at a later time.

Conclusion: Delays and potentially inaccurate results associated with unsats could increase the likelihood of a missed or delayed diagnosis. Unsats also impose burdens on the patients, their families, physicians, and the newborn screening program. Efforts to decrease the number of unsats could increase the timeliness and efficiency of newborn screening.

Public Health Implication: Newborn screening programs should be encouraged to work with hospitals to decrease the number of unsatisfactory specimens. This would help to decrease the potential for a child with a life-threatening or disabling illness to receive a delayed diagnosis and/or treatment. National policy guidelines need to be developed to help states to implement procedures to monitor and improve the quality of all aspects of the newborn screening system, from specimen collection to follow up.

The Effects of Parenting Practices, Maternal Depression and Other Sociodemographic Variables on Behavioral Health In White, African American and Latino Children

Authors: *L. Pachter, P. Auinger, T. Ghose, J. Harman, M. Weitzman*

Background: Parenting practices and characteristics (such as mental health status) are robust and significant contributors to child behavioral and developmental competencies. Most normative data on both parenting and child development comes from studies of the majority population demographic—middle class, White samples. Families living in other contexts (e.g., economic, social, cultural) are presented with unique conditions under which child development occurs. It is important to determine whether mediators and moderators of behavioral and developmental outcomes act similarly or differently in these contexts.

Method: Data from the National Longitudinal Survey of Youth (NLSY) was used. Information on parenting practices (using the HOME–SF inventory), maternal depression (CES-D), and child behavior (Behavior Problems Index: BPI, a 28-item maternal report instrument) was obtained on 903 White, 553 African American, and 415 Latino families with a child between 6-9 years of age. Additional variables studied included household structure (single vs. 2 parent), SES, and neighborhood characteristics. Data was analyzed via structural equations modeling, using AMOS 4.01 statistical software package

Result: In the total sample, the direct effect of maternal depression on child behavioral problems was stronger than the direct effect of parenting practices (HOME) on behavioral problems. The direct effect of maternal depression was greater than the effect of depression mediated through parenting. The direct effect of maternal depression on child behavioral problems was highly significant in all ethnic groups while the effect of parenting practices on child behavioral outcomes was not significant in the White and Latino families. Moderating effects of poverty and household structure were found.

Conclusion: Maternal depression is a salient predictor of child behavioral outcomes and is apparently stronger than the effects of parenting practices. Most of this effect is direct, and not mediated through parenting practices. One potential reason for this finding may be that depressed mothers may perceive and interpret their children's behaviors in ways that create reporting bias. Strength and significance of these effects, as well as with other sociodemographic variables, differ among ethnic groups.

Public Health Implication: Clinicians need to be aware of the mental health status of mothers when evaluating children for behavioral health issues, particularly when maternal report is relied upon.

The Health and Secondary Conditions Surveillance Instrument for Adults with Developmental Disabilities (HSCIADD) and Consumer Involvement In The Completion Process

Authors: *M. Traci, D. Bainbridge, T. Seekins*

Background: In 1996, we worked with our Developmental Disabilities (DD) Council to develop The Health and Secondary Conditions Surveillance Instrument for Adults with DD (HSCIADD) (Traci et al., 2002). In later years, with CDC funding, we further developed the tool and our descriptions of secondary conditions among adults with DD. This paper presents new data from an added item measuring consumer involvement in survey completion.

Method: HSCIADD items cover demographic, secondary conditions, and behavioral and environmental risk and protective factors. Current data were collected with 350 consenting adults consumers of state DD programs (Mage=.44.0(SD=14.8); 43.7% female; 6.4%Native American or Alaskan Native; 91.3% reported mental retardation as a primary disability) and their direct care providers. They completed surveys every three months for 15 months. In 2002, we added an item to estimate, on a 5-point scale, the "extent to which the consumer contributed ratings and input" to the completion of the survey (0= "no consumer input" to 4 = "total consumer completion").

Result: Consumers participated most in the completion process on the first and last surveys, with mean ratings ranging from .80 (SD=1.0) to 1.40 (SD =1.25). As hypothesized, consumers with mild overall disability severity participated significantly more than did consumers with moderate and severe disabilities, and consumers with moderate disability severity contributed more than consumers with severe overall disabilities ($F(2,293)=44.88$, $p < .05$). Also, consumer age ($r=-.19$), years of education ($r=-.26$), ratings of overall health ($r=-.20$) and independence ($r=-.35$), communication effectiveness ($r=.43$) and limitation associated with communication problems ($r=-.44$) were associated with the consumers' involvement in survey completion. Consumer involvement on the first survey (i.e., ratings >1) was correlated with summary scores reflecting completion of all five waves surveys ($r=.16$, $p<.05$).

Conclusion: Methods to measure the health of adults with DD must consider: 1) response biases associated with cognitive impairments (e.g., DeBettignies et al., 1990); 2) biases associated with proxy ratings (e.g., Todorov & Kirchner, 2000); and 3) self-determination's critical role in health management. More work is needed to further develop a measurement method that addresses these concerns and can be used for surveillance activities.

Public Health Implication: Very little is known about the specific health needs of this population. More surveillance work is needed to prioritize issues, improve programs and services, and evaluate outcomes. The reliability and validity of surveillance data are essential to sound program planning and policy decisions.

The ICF Version for Children and Youth: Field Trial Findings

Authors: *R. Simeonsson, F. Porter, D. Lollar*

Background: Documenting the nature and epidemiology of childhood disability has been complicated by variability of definitions and assessment tools. The publication of the International Classification of Functioning Disability and Health-ICF (WHO, 2001) offers a taxonomy to record health conditions and their consequences in adults. This presentation describes the development and field testing of a version of the ICF adapted for children and youth (ICF-CY). The draft version of the ICF-CY maintains the structure of the ICF with content modified to document health, functioning, disability and environmental factors from infancy through adolescence. All ICF codes applicable for children were retained with needed entries added such as behavior organization, sensory exploration, pre-verbal communication, motor coordination, symbolic and social play, and home, school and community environments. A related activity was the development

of questionnaires for four age groups; infancy (0-2), early childhood (3-6), middle childhood (7-12) and adolescence (13-18) to be used in assessing child functioning across domains of the ICF-CY.

Method: The draft version of the ICF-CY and related assessment materials are posted on the WHO website for field trials in the spring of 2004. Evaluation will take two forms, validation of content by expert review and applicability for clinical use. Parents, professionals and other stakeholders will be surveyed on the coverage and applicability of the ICF-CY for administrative, clinical and research settings. The ICF-CY will also be evaluated clinically using the four age-group questionnaires to code limitations of function, activities, participation and environmental factors in children with chronic conditions and disabilities.

Result: The ICF-CY and related field trial materials will be accessed by clinics, schools and other settings providing services for children in countries in all WHO regional sectors. Specific studies of the ICF-CY in several countries, including Italy, Sweden and the US will complement general field trial data. International as well as US data will be summarized to describe the sensitivity and comprehensiveness of the ICF-CY to code individual difference profiles as a function of age and health condition.

Public Health Implication: Validation of the ICF-CY and the parallel questionnaires in the field trials can provide a universal language and classification of childhood disability in public health surveillance and prevention. It can also promote the creation of measurement tools to advance parallel prevention and intervention activities in allied health disciplines, early intervention and special education.

The Impact of Intrauterine Exposure Versus Postnatal Environment In Children with Slight Brain Damage: Long-Term Neurobehavioral Studies

Author: *A. Ornoy*

Background: One of the consistent findings following exposure to major teratogens are significant morphologic and/or functional injuries of the central nervous system. In addition, there are many agents that cause only slight (and often clinically unnoticed) brain damage. The long-term development of children, especially at young age, is very much dependent on the environment the child is raised in. The influence of the postnatal environment is further illustrated by the fact that the neuro-developmental findings in young children are only partial predictors of their long-term development.

Method: In order to study the effects of the early environment on the development of children at high risk for neurodevelopmental problems, we performed a series of studies on the long-term development of children from 3 different groups: Children born to drug dependent parents, those born prematurely with birth weight of less than 1,500 grams and twins more than 20% discordant for birth weight. In all studies we used age appropriate neuro-developmental tests.

Result: We studied the development of children, from birth to 16 years of age, born to heroin dependent mothers raised at home in comparison to similar children adopted at a young age. They were also compared to control children, to those born to heroin dependent fathers and to children with environmental deprivation. These children were divided into three age groups: 0.5-6 years, 6-12 years and 12-16 years; altogether, 15 groups of children with 30-50 children in each group. We found that the children with environmental deprivation and children born to heroin dependent parents raised at home have lower intellectual and learning abilities in comparison to controls. However, the children born to heroin dependent mothers adopted at a young age, and raised in a good environment, functioned almost normally. The children born to heroin dependent mothers either raised at home or adopted also had a high rate of inattention and/or hyperactivity. The results in each one of these different age groups were similar. In the studies carried out on 50 children born prematurely with a birth weight of less than 1500 grams and compared to 50 matched controls, (all studying in regular schools) we found that the single parameter which predicted the intellectual outcome of the premature infants was maternal education. Children born to mothers with more than 13 years of education functioned normally. In the study on 72 pairs of monozygotic or dizygotic twins significantly discordant for birth weight, we found reduced psychomotor and mental scores in the smaller monozygotic twins at 1 and 2 years of age, but at 3 years of age the scores were the same in the smaller twins as in the larger, implying that the same home environment would similarly influence the development of the brain in both twins, and enable the smaller twin to overcome its developmental lag.

Conclusion: Our studies, therefore, emphasize the importance of a “good” and enriched environment on the development of young children, especially those at high risk for brain damage.

Public Health Implication: Our studies emphasizes the need to improve the environment in which children of high risk for neuro-developmental problems are raised, in order to enable them achieve their maximal potential. The cost benefits are obvious.

The Impact of Maternal Hypothyroidism During Pregnancy on the Developing Fetus: Considerations for Public Health

Authors: *M. Milton, C. Boyle, J. Hollowell*

Background: In the United States, between 12-16% of children younger than 18 years of age have developmental disabilities, including those that are neuropsychological in nature. Preventing such developmental disabilities is challenging as the etiology is often unknown. There is some scientific evidence to suggest that possible adverse neuropsychological development may be associated with maternal hypothyroidism during pregnancy. Hypothyroidism is associated with negative health outcomes for both the mother and child (e.g. placental abruption, pre-term labor, gestational hypertension). Currently, the obstetrics and gynecological community recognize thyroid disease as the second most common endocrine disease affecting women of reproductive age and suggest diagnosing and treating pregnant women with abnormal thyroid levels during pregnancy. The prevalence of thyroid deficiency is estimated to be between 2-2.5% among pregnant women in the United States. Increasing our understanding of the role of abnormal thyroid function during pregnancy on fetal outcomes may be an important step toward closing the knowledge gap to prevent developmental disability in the future.

Method: Over 40 of the world's experts in thyroidology, obstetrics and gynecology, child development, and public health were convened to assess 1) the prevalence of thyroid dysfunction in reproductive age women and factors associated with abnormal function, 2) outcomes related to thyroid dysfunction during pregnancy, 3) detection and treatment of thyroid dysfunction, and 4) considerations for public health practice.

Result: The results of the workshop hold important considerations for how public health can address this issue. The prevalence of hypothyroidism in reproductive age women for the United States of was documented. Abnormal thyroid functioning and risk factors for thyroid disease were described. The relationship between thyroid functioning and maternal/fetal outcomes was examined. Issues of detection of hypothyroidism in pregnant women and treatment were discussed.

Conclusion: The evidence is sufficient to support public health action to reduce the complications and adverse outcomes from hypothyroidism during pregnancy. Screening all women was not advised; however, women who are pregnant should be screened for thyroid abnormality as early as possible and treated. Further investigations are needed to find other factors to help identify populations at risk for hypothyroidism, standardize laboratory reference values, and document cost-effectiveness.

Public Health Implication: Prevention of hypothyroidism may be acheived through sufficient iodine intake at the population level and particularly for pregnant women. Identification and treatment of pregnant women with hypothyroidism during pregnancy may help prevent adverse outcomes for both mother and baby.

The Muscular Dystrophy Surveillance Tracking and Research Network (MD STARNET)

Authors: *C. Cunniff, F. J. Meaney, L. Miller, K. Mathews, P. Romitti, C. Druschel, A. Kenneson*

Background: Duchenne and Becker muscular dystrophy (DBMD), the most common forms of muscular dystrophy, affect about 1 in 3500 to 1 in 5000 male births. DBMD patients experience inter-clinic variation in treatment due to a lack of both information and consensus about the optimal care. State birth defects surveillance systems in the United States typically do not ascertain children with DBMD. Existing birth defects surveillance systems would need to be modified to accomplish population-based assessment of the impact of DBMD in states.

Method: The Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet) is designed to identify individuals with Duchenne or Becker muscular dystrophy (DBMD) with onset before age 21. The network currently includes AZ, CO, IA and NY. Potential sources to identify patients with DBMD include neuromuscular specialty clinics, service sites for children with special health care needs, and hospital discharge databases. The network teams have developed a case definition, surveillance protocol, computerized abstraction tool for on-site data entry by abstractors, and a pooled database. Comprehensive

data are abstracted from patient records of definite and probable cases, including demographics, treatments, and progression of disease. Abstracted data are reviewed by neuromuscular specialists to determine if the patient meets case definition. Families of patients will also be invited to participate in interviews to gather related data not found through patient record review.

Result: Data from MD STARnet will be used to (1) determine the prevalence of DBMD in different populations (2) describe the source, frequency, and type of preventive and medical care among persons with DBMD (3) determine the prevalence of related complications, and (4) assess the relationship between health outcomes and the source, frequency and type of preventive care received.

Public Health Implication: Programs designed to reduce the morbidity, mortality and costs of DBMD are currently limited by (1) insufficient data on the epidemiology of DBMD and its associated complications, (2) insufficient information documenting optimal methods of diagnosis and treatment, and (3) lack of systematic collection of outcome data under differing treatment and management regimens. Data collected through this program will provide a greater understanding of DBMD outcomes and may identify better treatments and prevention strategies to reduce secondary disabilities and adverse outcomes for patients with DBMD.

The National Smallpox Vaccine In Pregnancy Registry: Update on Women Inadvertently Exposed To Smallpox Vaccine and Their Early Pregnancy Outcomes

Authors: *M. Ryan, R. Aran, K. Campbell, S. Chow, A. Conlin, J. Strickler, K. Kenyan, J. Seward, M. Cano, J. Mulinare, P. Napolitano, B. Pierce, R. Engler, and J. Grabenstein*

Background: As part of nationwide efforts to prepare for bioterrorist threats, almost 100,000 women in the United States were vaccinated against smallpox in 2003. Recognizing that some inadvertent vaccine exposures to pregnant women would occur, the National Smallpox Vaccine in Pregnancy Registry was created.

Method: Detailed vaccination and pregnancy data are collected from healthcare providers, patients, and medical records, as well as the Vaccine Adverse Event Reporting System. When available, data on laboratory testing for vaccinia virus are included. The Registry also collects information on birth outcomes and infant health through the first year of life.

Result: As of January 2004, the Registry was following 211 women who were inadvertently exposed to smallpox vaccine in pregnancy. Most (95%) are military women and 5% are civilians. The average age of women in the Registry is 23 years and 63% are primigravid. Most of these women were exposed to smallpox vaccine before a standard pregnancy test would have been positive. Early evaluation of pregnancy outcomes has not revealed higher-than-expected rates of pregnancy loss, preterm delivery, or birth defects. Among pregnancy losses, laboratory diagnostics have not revealed vaccinia in four cases tested. No cases of fetal vaccinia have been identified.

Conclusion: Although outcomes of pregnancies inadvertently exposed to smallpox vaccine are reassuring to date, evaluation is ongoing. Continued analyses of birth outcomes and infant health are expected to be critical in understanding the current risks of smallpox vaccine to pregnant women.

Public Health Implication: This successful collaboration between military and civilian public health professionals highlights important nationwide efforts to respond appropriately to bioterrorist threats, including protecting pregnant women and their developing fetuses.

The Prevalence of Autism In Special Education

Author: *P. Shattuck*

Background: Virtually no research has been conducted into the prevalence of autism in special education – our nation's most widely available intervention entitlement program for children with disabilities. Added in 1991, autism is now one of the mandatory reporting categories under I.D.E.A. This report focuses on these questions: How has the prevalence of autism in special education changed from 1993 to 2002? How has this change related to other changes in special education prevalence? How has this change differed among states and cohorts?

Method: Annual prevalence estimates for 1993-2002 were computed using U.S. Department of Education counts of children enrolled in special education in the numerator, and corresponding Census estimates of population in the denominator. Time trends and variance

components were estimated with binomial growth models in HLM 5.0.

Result: Among children ages 6-11, autism prevalence grew 500% from 0.49 to 2.94 per 1,000. The prevalence of all children ages 6-11 enrolled in special education declined 2% from 110 to 108 per 1,000. The prevalence in almost all other eligibility categories also declined during this time. The growth in autism's administrative prevalence was not distributed evenly among states. In 2002, the prevalence among 6-11 year olds ranged from 0.83 in New Mexico to 6.11 in Oregon – more than a seven-fold difference. Cohort analyses revealed that autism prevalence tended to rise steadily within cohorts until leveling off in early adolescence. Each successive cohort examined exhibited higher prevalence than the ones preceding it.

Conclusion: Autism service counts have grown dramatically since the early 1990's. The fact that children continue to be identified well into the teen years suggests room for improvement in the accuracy and timeliness of identification efforts. Some weaknesses of these data include minimal standardization of procedures across sites, and lack of active case finding outside the bounds of the school context. However, one of the strengths of these data is the coverage of a very large proportion of the general population of children. Recent surveillance findings suggest that despite problems with these data, the autism special education counts tend not to identify children who do not really have autism - specificity appears high while sensitivity is low. It is worth considering these data for questions related to the timing of identification, cost of illness, and geographic variations in prevalence.

Public Health Implication: NCBDDD now funds autism surveillance projects in 16 states. The variability among states and the continued identification of children into the teen years in the schools data suggests that surveillance efforts should pay careful attention to the potential for true variability among locales, cohorts, and ages.

Thyroid Hormones in Pregnancy and 1-Year Post Partum. Reference Ranges Using Isotope Dilution Tandem Mass Spectrometry: A Longitudinal Study and Comparison with Immunoassays

Authors: *O. Soldin, L. Hilakivi-Clarke, S. Soldin*

Background: Thyroxine (T4) and triiodothyronine (T3) are essential for the regulation of biological processes, including carbohydrate metabolism, oxygen consumption, protein synthesis and growth. Adequate thyroid hormone concentrations are critical for normal fetal neurodevelopment. Using innovative techniques, we studied will and define here the reference ranges of T4 and T3 concentrations of normal, iodine-sufficient women during the first, second and third trimester of pregnancy and one-year post-partum.

Method: We measured T4 and T3 simultaneously by isotope dilution tandem mass spectrometry. The new reference ranges during pregnancy (first, second and third trimesters) and one-year post-partum were established. We compared the tandem mass spectrometry results with those obtained by immunoassay on the same samples.

Result: Bloods were drawn from normal, iodine sufficient women during different stages of pregnancy. API-3000 tandem mass-spectrometer (SCIEX, Toronto, Canada) equipped with TurboIonSpray and Shimadzu HPLC system was used employing isotope dilution with deuterium-labeled internal standard (L-thyroxin-d2) in the negative mode.

Conclusion: We determined new reference ranges for thyroid hormone concentrations in women during the first, second and third trimester, and one year post partum, using isotope dilution tandem mass spectrometry. T4 and T3 were determined simultaneously in serum, free of interference by nonspecific binding heterophilic antoibodies and autoantibodies. These results were compared to immunassays of the same samples. For T4 the slope of the linear regression decreased from 1.10 in non-pregnant women to 0.83-0.90 during pregnancy. For T3, correlations between MS/MS and immunoassays were poor in all cases.

Public Health Implication: Adequate maternal thyroid hormone concentrations are critical for normal fetal brain development, at least until midgestation. T4 and T3 measurements can be used for thyroid function evaluation and diagnosis of disease. This state-of-the-art method for thyroid hormone detection allows fast simultaneous detection with great specificity, sensitivity and precision.

Transcultural Training For Community Based Perinatal Health Care Providers

Authors: *M. C. Glick, B. Hughes, S. Sorkin, M. Martin, Y. Lai, K. Stevens, and B. Sumrall Smith*

Background: The health care system is serving an increasingly diverse population, with little formal training in place to improve caregiver's knowledge and expertise in transcultural relationships. The United States is possibly the most culturally diversified nation in the world. It is clear that health outcomes of underserved populations are particularly adversely affected by cultural discrepancies, miscommunication and misunderstandings between of the provider and patient.

Method: Facilitation of effective transcultural communication to improve relationships between providers and patients of different cultural backgrounds is the first step in reducing disparate outcomes of ethnic and minority populations. It is anticipated that these efforts will lead to improved partnerships in health decision making between providers and their patients, thus improving overall health. In 2001, National Perinatal Association introduced the handbook, "Transcultural Aspects of Perinatal Care, A Resource Guide©."

Result: As a result of the research and development of this publication, the National Perinatal Association is offering professional education, working toward improved cultural awareness and competence of providers. The initial phase is to gain an understanding of those cultures with whom the providers are working. National Perinatal Association has further determined that practical transcultural skills are needed to improve the health care encounter and its outcome for patients and their families. Recognition of the individual and the institutional needs for such skill building will be achieved in this session.

Conclusion: The National Perinatal Association has begun a training program called "Transcultural Education: A Journey to Cultural Competence ©", in addition to the publication of the handbook, "Transcultural Aspects of Perinatal Care; A Resource Guide©."

Public Health Implication: The purpose of these two projects is to improve transcultural relationships between providers and patients through introduction of a nationwide training program designed for perinatal health care professionals.

Understanding The Contextual Factors That Influence The Presence of Secondary Conditions For People Who Experience Spinal Cord Injuries

Authors: *L. Powers, D. H. Westwood*

Background: In the last decade, the health status of individuals with disabilities has emerged as an explicit focus of public health attention, with consumers, policymakers, and researchers joining in defining and implementing an agenda in this area. (Andresen, Lollar, and Meyers 2000; Lollar 1994; Pope1992; Seekins, White, Ravesloot, et al. 1999; Simeonsson and McDevitt 1999; Tanenhaus, Meyers, and Harbison 2000). This study is investigating the role of general health maintenance activities and environmental or contextual factors (e.g. access to personal assistance services, health provider communication) in facilitating or impeding individual's health and wellness, particularly their experience of SCI-related secondary conditions. Findings will describe the contribution of demographic, general health maintenance and contextual to the presence of secondary conditions.

Method: 300 adults completed a 100 question SCI Survey, with validated measures of general health maintenance and additional context-related items derived from prior research on SCI across the US. Durable Medical Equipment (DME) suppliers (geographically representative) recruited subjects, using ICD-9 codes for SCI's. This methodology enabled the survey to reach a broad spectrum of people with SCI and key demographic data available on the DME population recruited to the study, which can be compared with the responding sample (e.g., age, gender, public / private health insurance, urban /rural).

Result: Findings will inform: 1). The contribution of a person's engagement in general health behaviors in predicting the occurrence of secondary conditions; 2). The contribution of contextual factors in predicting secondary conditions, and 3). The contribution of contextual factors in predicting secondary conditions when controlling for engagement in general health behaviors.

Conclusion: Understanding of health for persons with SCI's has expanded beyond disease management and rehabilitation to incorporate access to routine health care, wellness promotion, and prevention of secondary and other conditions. Elucidating these to maximize their health and wellness is critical.

Public Health Implication: The findings will facilitate the identification and implementation of community actions, which can reduce the influence of contextual factors that prevent people with SCI from staying as healthy as possible.

Understanding Unintended Pregnancy: Improving Infant Health

Authors: *J. Santelli, B. Colley Gilbert, R. Rochat, K. Hatfield-Timajchy, K. Curtis, R. Cabral, J. Hirsch, L. Schieve, S. Zane, P. Stupp, and M. Schauer*

Background: Unintended pregnancy is a core concept for describing the fertility of populations and the unmet need for contraception. Understanding unintended pregnancy may also be helpful in preventing adverse health impacts such as birth defects. However, the role of intention in determining fertility decisions and prenatal behaviors such as folic acid use is not well understood.

Method: As part of a Division of Reproductive Health strategic planning effort, we reviewed the published and unpublished literature and consulted with experts in the area of pregnancy intentions. Standard electronic bibliographic databases such as Medline were used. We will discuss findings and implications from this review.

Result: Current measures of unintended pregnancy are reliable and predictive on a population level but not designed to be used at an individual level. Many women report that pregnancy is not a planned event; in addition, measures of pregnancy intention often fail to incorporate male partner intentions. Although commonly reported as a dichotomous variable, pregnancy intentions are increasingly seen as multidimensional, encompassing affective, cognitive, cultural, and contextual dimensions. Unintended pregnancy is associated with a variety of health-compromising maternal behaviors and may be related to poor infant outcomes.

Conclusion: Clarifying issues of meaning and measurement is fundamental to developing a more complete conceptual framework for understanding unintended pregnancy.

Public Health Implication: Increased understanding of pregnancy intention could advance efforts to prevent unintended pregnancies, promote healthy prenatal behaviors, and improve the health of women and children.

Using Community-Based Participatory Action Research (PAR) In Disability Health Promotion

Authors: *M. Neri, T. Kroll, G. Jones, M. Goldstein, S. Michael*

Background: Adults with physical disabilities use primary prevention services at rates well below national recommendations and guidelines. One of the objectives of this project is to explore the use of community-based participatory action research (PAR) strategies in the education of people with physical disabilities and their health care providers about utilization of primary prevention services. The ultimate goal is to reduce the incidence of costly secondary conditions and associated health care expenditures, as well as to enhance long-term health and well being.

Method: The study is being conducted in four urban, suburban and rural counties of Northern Virginia. The study uses the following community-based PAR strategies: (a) focus groups to identify consumer prevention priorities and barriers; (b) a consumer steering committee to advise research staff on methodological and practical research issues; (c) employment of community-dwelling individuals with disabilities on the research team; (d) beta field testing of resource materials on primary prevention to generate consumer feedback; (e) qualitative and quantitative research methods integrated within a coherent consumer-directed and community-based PAR framework.

Result: The use of community-based PAR maximizes consumer participation in the research and development of health promotion tools for use by adults with physical disabilities and their health care providers. The participatory approach ensures relevance, utility and ecological validity of materials for consumers with physical disabilities. Simultaneously, it empowers them to take an active role in health promotion and increases their use of preventive health care services.

Conclusion: Community-based PAR is an inclusive strategy that can help to achieve optimal consumer input into the research and development of health promotion and prevention tools for adults with disabilities and their health care providers.

Public Health Implication: Public health promotion strategies for all people with disabilities should incorporate community-based PAR practices that have been developed with the assistance of individuals with disabilities, and not just health care professionals, policy

makers, and researchers. Public health care practices and recommendations should reflect the input and understanding of the target audience being served, e.g., health practices for people aging with disabilities should be developed with individuals who have been living with long-term disabilities.

Using Geographic Information Systems To Link Data From The South Carolina Autism and Developmental Disabilities Monitoring Network With Available Environmental Data

Authors: *L. King, J. Nicholas, L. Arnstein, W. Jenner, J. Charles*

Background: There has been much speculation in the media regarding the association of pesticides and mercury with the development of autism. The purpose of this study is to use Geographic Information Systems (GIS) to link existing environmental data in South Carolina with data obtained from the South Carolina Autism and Developmental Disabilities Monitoring Network (SCADDM). SCADDM primarily focuses on establishing the prevalence of autism spectrum disorders (ASDs) in the Coastal and Pee Dee regions of South Carolina.

Method: This is an ecological analysis of existing environmental data from the South Carolina Department of Health and Environmental Control (DHEC) and from data obtained from SCADDM. Records of children seen in medical facilities or served in the special education system or disability boards will be reviewed to determine whether they meet criteria for ASD surveillance case definition. Data on mercury and PCB exposures in the waterways of South Carolina have been obtained. Review of all data and information from these two sources will be disseminated together into visual graphs and maps that will provide a comparison of areas with various environmental exposures to the location of children with an ASD.

Result: In South Carolina, conditions that favor the conversion of mercury to methyl mercury are found in large number and density throughout the state. Currently, mercury has been found in 42% of sites investigated, and fish consumption advisories exist on 52 state water bodies because of mercury contamination. These waterways were mapped and will be compared to the location of children with an ASD.

Conclusion: Results will show possible associations between various environmental exposures and the location of children with ASD. Various implications will be discussed.

Public Health Implication: Autism and its spectrum disorders have emerged as an increasingly important public health concern in the United States. It is important to consider the potential environmental risk factors that could be associated with these disabilities. SCADDM is the only surveillance system of developmental disabilities within the state. Although this analysis is ecological and cannot be generalized at the individual level, it is an important first step in establishing hypotheses that may be further examined in the future.

Using the PPOR Approach to Implement Preconception Health Policies and Programs

Authors: *M. Peck, D. Bara, C. Brady, J. Skala*

Background: CityMatCH has worked with CDC, March of Dimes and community partners since 1997 to define, test and disseminate the Perinatal Periods of Risk (PPOR) Approach in U.S. urban communities to improve women's and infants' health. CityMatCH utilized its Practice Collaborative (PC) model to facilitate translation of knowledge into prevention of feto-infant mortality.

Method: The Practice Collaborative provides selected community action teams with strategic leadership, scientific support, effective cross communication, structured peer exchange, continuous assessment and promotion of data driven policy and program decisions. The 2000-2002 PPOR-PC enabled 14 U.S. urban communities to translate knowledge into action through the six-step PPOR approach. The teams followed together over two years to build community and analytic "readiness," map and further investigate feto-infant mortality, translate findings into targeted community-driven actions, and evaluate impact.

Result: All PPOR-PC cities found the widest gaps and greatest excess feto-infant deaths in the "Maternal Health/Prematurity" (<1500g) Period of Risk. Assessing and improving "community readiness" for change fostered greater mobilization and engagement of key partners. Attention to analytic readiness increased local and state data capacity. Cities' specific focus on <1500g deaths yielded targeted prevention strategies, notably preconception health. Several communities developed new programs emphasizing preconception care (.e.g. Jacksonville's Magnolia Project) and leveraged policy shifts toward supporting interconception care based on PPOR findings. PC participation and concurrent use of

PPOR approach accelerated local use of PPOR to drive public policy for perinatal health, especially in Florida, which subsequently replicated the PPOR-PC model in all urban areas.

Conclusion: PPOR implemented through the CityMatCH Practice Collaborative model was effective for developing community-driven prevention for women and infant's health, with emphasis on pre-/ interconception care strategies. Florida's communities illustrate strategic use of data for action.

Public Health Implication: Implementation of the six-step PPOR approach, not just feto-infant mortality data, stimulated new and/or strengthened existing community partnerships to improve women's and infants' heath. Participation in multi-community Practice Collaborative models can accelerate data-drive, community-based change.

Utilization of Birth Defects Data Through Collaborative Research Projects

Author: *S. Viner-Brown*

Background: The National Birth Defects Prevention Network (NBDPN) is a national network of state and population-based programs for birth defects surveillance, research and prevention. Its overall goals are to assess the impact of birth defects upon children, families, and health care; identify factors that can be used to develop primary prevention strategies; and assist families and their providers in secondary disabilities prevention. To help achieve these goals, the NBDPN encourages state birth defects surveillance programs to participate in collaborative research to help understand the causes, occurrences and consequences of birth defects.

Method: All study proposals are presented to the NBDPN State Data Committee with final approval given by the Executive Committee. Collaborative projects are tracked in a database that includes purpose, timeline, and participating states. Projects seek broad participation from state programs both in planning and data submission. Standardized data transmission formats with variable definitions and file layouts are developed for each project.

Result: The NBDPN has coordinated or participated in the following national and international projects: rapid ascertainment of neural tube defects; WHO's International Database on Craniofacial Anomalies; contribution of birth defects to preterm birth (in partnership with the March of Dimes); trends in gastroschisis; mortality rates among infants with neural tube defects; etc. The NBDPN uses peer-reviewed journals to disseminate findings.

Conclusion: Collaboration and data sharing facilitate: 1)improvements in the quality of birth defect surveillance data, 2) promotion of scientific collaboration for the prevention of birth defects, 3) facilitation of collection, analysis and dissemination of data and information related to birth defects, and 4) provision of technical assistance for the development of uniform methods of data collection. The NBDPN can provide technical assistance in study design, data analysis, and dissemination to further the development of collaborative studies.

Public Health Implication: The utilization of birth defects data is critical to carry out the core public health functions of policy development, program/services planning, and assurance.

Validation of Information on Birth Defects Registry with Vital Records

Author: *C. Liu*

Background: The birth defects surveillance system in Connecticut, which is known as Children with Special Health Care Needs (CSHCN) Registry, is in its second year of collecting information on all birth defects occurred statewide. Records submitted from birth hospitals to the Connecticut Department of Public Health through newborn screening programs are a major data source for CSHCN Registry. Information on Electronic Vital Records (EVR), which is deemed as gold standard, is used to validate records submitted by hospitals before they can be incorporated into the CSHCN Registry. In this study, we compared the birth defects data submitted by the University of Connecticut Health Center (UCHC), one of the largest hospitals in Connecticut, with EVR for information on demographic, geographic, and birth defects diagnoses.

Method: We linked the birth defects records submitted by UCHC for the years of 2002-2003 to EVR by unique Accession Number. Results of this linkage were stratified by child's sex, race, care unit, and CSHCN referral status, along with 95% confidence intervals to illustrate the precision of the estimates. Information examined included child's demographic and birth weight, mother's demographic and geographic, and birth defects

diagnoses. Sensitivity and positive predictive value are used to ascertain the birth defects diagnoses on EVR.

Result: There were 227 birth defects records submitted by UCHC for this time period, among which, 169 records (74.4%; 95%CI: 68.7%-80.1%) could be linked to EVR by unique Accession number. Despite the variations that exist by sex, race, care unit, and CSHCN referral status, none of these differences were statistically significant. The agreements on child's demographic and birth weight, and mother's demographic and residence were high with few cases where information on EVR is thought to be more reliable. The sensitivity and positive predictive value for birth defects diagnoses on EVR were 75% and 100% for Down syndrome respectively, and were both 100% for cleft lip/cleft palate. These are birth defects evident at birth and should be recorded on EVR.

Conclusion: EVR can be a good source to supplement information to birth defects registry on child and mother's demographics, as well as birth defects diagnoses that are evident at birth.

Public Health Implication: Caution should be exercised before this information is used to enhance the birth defects surveillance system for planning, resource allocation, and epidemiological studies, as the quality of other information may be questionable.

Weaving A Successful Data Integration Project

Authors: *J. Eichwald, D. Ross*

Background: In response to the National Task Force on Newborn Screening report, All Kids Count (AKC) in partnership with the Genetic Services Branch, Maternal and Child Health Bureau of HRSA undertook the task to identify and describe some of the best practices for integrating newborn screening information with other early childhood health information systems. Regardless of its scope or focus, a few key elements were identified that are felt to be critical to the successful implementation of an integration project. These elements are not technical, but cross-cutting organizational considerations. The nine key elements as follows are: Leadership, Project Governance, Project Management, Stakeholder Involvement, Organizational and Technical Strategy, Technical Support and Coordination, Financial Support and Management, Policy Support, and Evaluation. Those interested in successful planning and implementation of data integration projects need to consider weaving these key elements into the fabric of an organization.
In keeping with the theme of weaving, the Navaho people create some of the highest quality weavings ever produced. Not only are their weavings a very important source of tribal income, they are a device to keep Navaho traditions alive and to communicate their culture to the world. This presentation will employ the interpretation of several Navaho weavings to illustrate how one state, Utah, was able to successfully organize the key elements in the integration of child health information systems.

What is the Public Asking about Early Hearing Detection and Intervention?

Authors: *M. Victor, B. Guajardo*

Background: The Centers for Disease Control and Prevention's Public Inquiry System allows the EHDI program to communicate many health messages to diverse audiences through different media, including: internet, email, fax, phone/Text Telephone (TTY) service, and a toll-free hotline. Participants will gain an understanding of the structure of the inquiry system and the topics on which the inquiry system frequently receives questions from the United States and globally. The objectives are as follows:
1.) Describe the CDC-EHDI Public Inquiries System
2.) Discuss the frequently asked questions that are received and responded to by the CDC-EHDI program.
3.) Demonstrate the importance of putting information in readable, plain language and utilizing the internet to disseminate important questions and answers related to EHDI.

Method: Through review of the inquiries the participants will gain insight into what questions families, health care providers, and students are asking about hearing loss, newborn hearing screening, resources/services, and EHDI related research.

Result: The materials disseminated through the inquiry system will be shared with the participants, as well as the newly developed frequently asked questions section designed for the CDC-EHDI website.

Conclusion: To conclude, the presentation will describe the CDC-EHDI program's on-going health education and communication efforts in the development of messages and materials that are accurate and easy-to-read.

Public Health Implication: Public health programs can more effectively respond to the community they serve by utilizing a system such as the one described to relay accurate and relevant health messages.